

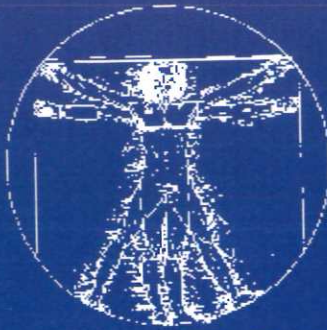
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 1998*

Mid-Atlantic Ethics Committee
Newsletter, Summer 1998

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

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

Summer 1998

MORAL MUSINGS: THE SOUL OF A HOSPITAL

Inside this issue:

The Soul of a Hospital	1
Network News	2
Bioethics 2000 at the Science Museum of Virginia	4
Maryland Project on Care at the End of Life	4
Case Presentation	5
Case Discussion:	
Comments From a Bioethicist	6
Comments From a Hospital Chaplain	7
Ethics Committees and Consultants in Health Plans	7
RWJ End of Life Project	8
Do You Work in an Ethical Organization?	9
Calendar of Events	10

If the human soul is that part of our inner selves that seeks to harmonize our conscious notions of what is right and good with our behavior, then we might think of the soul of a hospital as the ethics of its administration. That is, the soul of a hospital can be conceptualized as the hospital's administrative will to right action in the face of moral challenge. This includes administrative actions at the macro-administrative level, i.e. at the level of institutional ethos as manifested through the hospital's mission and goals statements that the hospital projects into the outside world. This also includes administrative actions at the micro-administrative level, i.e. at the level of policies and procedures that formally direct the actions of hospital staff and other affiliated individuals. And last, this includes administrative actions at the mini-administrative level, i.e. at the level of personal interactions that occur in the course of the conduct and management of every day activities.

Moral challenge can be highly visible, such as when a hospital is embroiled in controversy or scandal that extends past its walls. Actions

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

taken in the face of these kinds of moral challenges either solidify or weaken a hospital's administrative moral strength. For example, in the recent tragic death of a young boy in Chicago, a hospital refused to go outside its Emergency Room doors to bring in a child with a gun shot wound that the boy's playmates had carried to the hospital. Although the child eventually gained Emergency Room entry, he died hours later. How the hospital addresses this scandal, I suggest, will influence the future moral well-being

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Diane E. Hoffmann, J.D., M.S., Editor
Evan G. DeRenzo, Ph.D., Co-Editor
Laura Callahan, R.N., Student Editor
Nancy Zibron, M.A., Layout Editor

Contributing Editors:

Louis Breschi, M.D., Member, Ethics Committee, Franklin Square Hospital

John Fletcher, Ph.D., Director, Center for Biomedical Ethics, University of Virginia

Sigrid Fry-Revere, J.D., Ph.D., Independent Bioethics Consultant

Jacqueline J. Glover, Ph.D., Associate Director, Center for Health, Ethics and Law, Robert C. Byrd Health Sciences Center of West Virginia University

Edmund G. Howe, M.D., J.D., Director of Programs in Medical Ethics, Uniformed Services University of the Health Sciences

Sanford Leikin, M.D., Adjunct Medical Officer, Office of Protection of Human Subjects, National Institutes of Health

Joan Lewis, Coordinator, Washington Metropolitan Bioethics Network, D.C. Hospital Association

Steven Lipson, M.D., Medical Director, Hebrew Home

Franklin Miller, Ph.D., Bioethicist, Member, NIH Clinical Center Bioethics Committee

Jack Schwartz, J.D., Chief Counsel, Division of Advice & Opinions,

Maryland Office of the Attorney General

Ian Shank, M.D., Member, Fairfax Hospital and Reston Hospital Center Ethics Committees

Henry Silverman, M.D., Chair, Ethics Committee, University of Maryland Medical System

Peter Terry, M.D., Member, Johns Hopkins Hospital and Francis Scott Key Medical Center Ethics Committees

Jan Vinicky, Ph.D., Bioethicist, Washington Hospital Center

Margot White, J.D.

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 410/706-7239

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NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHCECN)

On May 30, 1998, the Maryland Health Care Ethics Committee Network, in conjunction with the Anne Arundel Medical Center, sponsored a half day workshop entitled, "Life and Death: Whose Decision is it Anyway?" Those attending participated in lively discussions on issues surrounding competency, advance directives, research on end of life decision making and the evolving roles of physician and families in decision making. A day long workshop is being planned for the fall. If you did not receive an announcement for the spring workshop, please contact Anne O'Neil at (410) 706-4485 to be placed on the mailing list for the fall conference.

The Network in conjunction with the University of Maryland Law & Health Care Program is in the process of conducting a study of relevant knowledge and skills of individuals conducting ethics committee consultations in Maryland hospitals. The study is being funded by the Greenwall Foundation and consists of two questionnaires. The first questionnaire, to be completed by committee chairs, has been mailed out. Responses from this mailing will provide the names of committee members participating in patient care consultations. These individuals will then receive the second questionnaire directed toward their own experiences and knowledge of the consultation process. The Network anticipates that results of the study will be available in the fall. After the study is completed, the Network hopes to conduct a second study of the results of an educational intervention for individuals conducting ethics consults. If you chair a hospital ethics committee in Maryland and have not received the first questionnaire, please contact Anne O'Neil at the number listed above.

Metropolitan Washington Bioethics Network (MWBN)

The MWBN will not be meeting this summer but will start up again in September. Its next meeting will be held on September 23rd at 12:00 noon in conjunction with Washington Hospital Center's 6th Annual Henry D. Ecker Lecture. The speaker will be Ira Byock, MD, Director, Palliative Care Service, Missoula Montana. For more information call Sue Edwards at 202-877-6211. The date for the October meeting has not yet been set but the topic will be "restraints." For further information call Joan Lewis at 202-682-1581.

The Network has also applied for a Robert Wood Johnson Foundation grant under its initiative—Community-State Partnerships to Improve End of Life Care. (See article on page 8.)

Virginia Center for Biomedical Ethics (VCBE)

The Virginia Center for Biomedical Ethics is moving fast and forward to join the ranks of top academic centers and programs in the country. The Center's current strengths lie in their Ethics Consultation Service, medical school's Bioethics course, graduate level training program and the Center's Outreach Programs. Building on these successful programs, the Center plans to re-cast the graduate program into a certificate in Bioethics rather than clinical ethics to broaden its reach. The medical school's Bioethics course may be one of the elements integrated into a new first course on *The Doctor, the Patient and the Illness*. Additionally, the Center plans to develop a major research effort, with special emphasis on outcome studies, the ethics of human subjects research, and ethical issues in genetics.

The Soul of a Hospital

Cont. from page 1

of the hospital. For example, how the hospital addresses community concerns, such as holding or not holding community meetings, will affect staff morale and staff ability to engage in right action under pressure in the future. If the hospital makes excuses for its refusal to treat, there may be a scandal that permanently decreases quality of care in the hospital.

On a micro-administrative level, hospital policies and procedures forcefully shape the moral fabric of a hospital. If, for example, a hospital has an ethics committee (EC), what are the procedures for triggering an EC consultation? My sense is that in hospitals where ethics consultations can only be brought by physicians, ethics consultation is a sham. Such a policy makes the prospects for serious discussion of disputed moral judgments a joke and serves only to deepen staff cynicism. Only in hospitals where everyone - including housekeepers and maintenance personnel - is not only procedurally permitted but openly encouraged to bring ethics consultations forward can a hospital be seen as putting teeth into its ethics policies and procedures. And only when a hospital's ethics consultation policies and procedures have teeth, will ethics policies contribute to enhancing the moral will of an institution.

Finally, onto the day to day grind. A hospital's soul is shaped daily through the resolution of the everyday issues that are part and parcel of patient care. As the quality of the human soul is often revealed through the acts of decency and courage exhibited by individuals towards others, so too is a hospital's soul revealed in the actions individuals take to elevate the level of moral discourse within the facility.

Actions taken at the individual administrative level, what I've called the mini-administrative level, can be soul nurturing or soul deadening. Just as the human soul can be crushed, so too, I suggest, can the soul of a hospital. The accumulated effects of moral blindness

or weakness of moral will on the part of a hospital's managers can blunt a hospital's moral core.

Soul deadening behavior on the part of administrators are those that produce fear. Fear and intimidation - and tolerance of intimidation - cripple organizational, as well as human, spirit. Systems designed to foster sound moral judgment are enlivened only in an

"And only when a hospital's ethics consultation policies and procedures have teeth, will ethics policies contribute to enhancing the moral will of an institution. "

atmosphere free from fear and intimidation. The inclination to speak-up, to explore the need for change, and to question must be habituated and rewarded - never the reverse.

A classic example of the insidiousness of even the tolerance of intimidation and the chilling affect it has on the level of moral discourse within an institution is a case known to many. Let's imagine a hospital that includes members of the hospital's EC on its Intensive Care Unit (ICU) rounds. The EC member on ICU rounds is a nurse, the debate is about continuing aggressive intervention. At the outset, the attending physician wants to keep going, much of the rest of the team wants to start withdrawing, and there are a couple of fellows who seem ambivalent. The EC member is, herself, undecided at the beginning of the discussion, but she feels compelled to make explicit and clarify the various positions. As the discussion unfolds, consensus develops to withdraw aggressive interventions, with the attending physician the only player who wants to continue to want to push ahead. The attending ends the discussion, curtly. Later in the day, the attending

goes to the EC member's boss and complains that he (the attending) finds the EC member difficult to work with and generally uncooperative, without specifically mentioning that morning's rounds.

What this boss does will determine whether moral will in the institution will be enhanced or decayed. It is simply not enough to have the EC member's boss smooth out the attending's ruffled feathers and tell the EC member not to worry about it. If that is all that occurs, the incident will put a pall on ethics discussions at ICU rounds, at the very least. It will fly through the hospital's ethics grape vine that the

hospital only gives lip service to airing moral disagreements and that those in power are to be deferred to with little or no challenge. If, however, the EC member's boss were to say, "I appreciate your comments. But if you have a problem with Ms. Smith, you need to talk to her directly about your concerns. I am happy to join in that discussion if you wish," the dynamics of the interchange would send a clear message throughout the hospital that power legitimately grounded in knowledge does not translate into illegitimate power to squash moral discourse.

The human soul is fragile. It needs protection and nourishment to flourish. The same can be said for the soul of a hospital. It is the ethical conduct of a hospital administration that feeds a hospital's soul.

Evan G. DeRenzo, Ph.D
Bioethics Program
National Institutes of Health
Clinical Center

BIOETHICS 2000 AT THE SCIENCE MUSEUM OF VIRGINIA

The Greenwall Foundation, a private foundation supporting the arts and humanities, education, and medicine has awarded the Science Museum of Virginia a two-year grant of \$77,575 for *BIOETHICS 2000: Ethical Issues in Organ Donation and Transplantation, and Genetics*.

The Greenwall Foundation grant will allow *BIOETHICS 2000* to continue and enhance collaborations dedicated to education in bioethical issues associated with organ/tissue donation and transplantation, and genetics. The Science Museum of Virginia's collaborators in *BIOETHICS 2000* are the United Network for Organ Sharing, Southern California Organ Procurement Center, Virginia Transplant Center, Virginia Commonwealth University, Medical College of Virginia, Virginia Biotechnology Research Park, and Mills Godwin High School. The collaborative project is designed to increase public understanding of bioethical issues in organ/tissue donation and transplantation, and genetics in order to establish a foundation for sound judgment and responsible action in public policy. The project promotes access to information, public education, values-based discussions, and provides information on health care delivery systems, and health care and cost implications to underlay public health policy education.

The grant provides funding to produce and perform a play on the bioethical issues and perspectives in organ donation and transplantation; create and distribute a videotape of the play; host teacher workshops to provide teachers with the skills necessary to lead bioethical discussions in genetics and organ donation and transplantation; heighten teacher awareness of materials available on ethical issues in organ donation and transplantation, and genetics; host a lecture series featuring panel discussions by genetic counselors, health care

providers, clergy, physicians, and lawyers on the ethical issues raised by advances in genetic research and its application to genetic counseling for the general public and allied health care providers; host workshops on bioethical issues in reproductive medicine and genetic counseling for allied health care providers; and publish a completed teacher resource curriculum guide in genetics.

A complete listing of program topics, dates, and times will be posted on the Science Museum of Virginia's website in October. If you would like to be on the mailing list for all programs, send your name, email, and/or postal address to:

Eugene G. Maurakis, Ph.D.
Science Museum of Virginia
2500 West Broad Street
Richmond, VA 23220
maurakis@smv.mus.va.us

The Greenwall Foundation

The Greenwall Foundation focuses grants on medical research and education. The Foundation's bioethics grants support efforts of physicians, lawyers, philosophers, economists, theologians and other professionals to address micro and macro issues in bioethics, with the goal of providing guidance for those engaged in decision making at the bedside and shaping institutional and public policy. The Foundation's medical research grants aim to stimulate applied research; develop education programs for health professionals and lay people; encourage intra- and inter-institutional, regional, national, and international collaboration; foster public discussion of issues and policy to assure information is used to benefit individuals and society; and develop and evaluate standards of behavior and policy. The Foundation aims, through its education grants, to help individuals achieve their full potential and a better quality of life.

MARYLAND PROJECT ON CARE AT THE END OF LIFE

The Maryland Attorney General's Project on Care at the End of Life is up and running. Jack Schwartz, Chief Counsel for Opinions and Advice, has been coordinating the effort during the past year and the Project has initiated a number of efforts to better understand the obstacles to adequate end of life care in the state and to address some of those obstacles. One of the most ambitious efforts of the Project has been a state wide survey of health care providers regarding their perceptions of problems in end of life care. The survey is being conducted by the Bioethics Institute at Johns Hopkins and is being funded by a "planning grant" from the Robert Wood Johnson Foundation. The survey was sent to physicians, nurses and social workers throughout the state. One of the questions included on the survey is "Which of the following do you consider a serious problem in care at the end of life?"

- a. proper pain management
- b. identifying the decision maker for the patient
- c. differences among family members regarding treatment decisions
- d. psychological problems of the patient
- e. psychological problems among family members
- f. communication between physician and patient
- g. communication between physician and family members
- h. cost of care
- i. interdisciplinary coordination among health professionals

Respondents are asked to identify which of these is the most significant. They are also asked to specify how important they think legal concerns are in the treatment of patients at the end of life and how they think legal concerns

influence end of life decisions. In addition, they are asked specific questions about pain management and problems with advance directives. Finally, they are asked about their perceptions of ethics committees in resolving conflicts over patient care and what problems they see with ethics committee consultations. So far, over 1800 responses have been received. The final results are expected to be available in the fall and will be reported in a future issue of the Newsletter.

Other initiatives of the Project include a Palliative Care/Pain Management Hot Line. Dr. Michael Gloth, Chief of the Division of Geriatrics at Union Memorial Hospital, established the hotline in March. According to Dr. Gloth, with the help of the Maryland Institute for Emergency Medical Services Systems and publicity efforts by the Board of Physician Quality Assurance and Med-Chi, the hotline has been receiving a steady volume of calls. Dr. Gloth is currently preparing a brochure about the hot line.

Finally, the Project has taken a leadership role in bringing together researchers at Johns Hopkins Schools of Medicine and Public Health and the University of Maryland Schools of Medicine and Law as well as representatives from relevant provider and consumer groups throughout the state to submit a grant proposal to the Robert Wood Johnson Foundation under its initiative: Community-State Partnerships to Improve End of Life Care. (See article on page 8.)

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 District of Columbia Hospital

Ms. L is a 39 year-old paraplegic who has been wheelchair bound since childhood as a result of spina bifida. She has had a number of problems over the years as a result of her medical condition including multiple infections and decubitus ulcers. She is also chronically anemic. Ms. L lives with her mother and her two sisters. Although they are available to help her when needed, she manages most of her activities on her own. In fact, during the day she cares for her sisters' children while her sisters and mother are at work. She is an intelligent and articulate woman who has educated herself well especially with regard to her medical issues.

Ms. L was raised in the Methodist tradition. About 6 years ago, however, she became a Jehovah's Witness. Her faith is very strong and she is a very active member of her congregation. She feels that her religion provides her with

a great source of strength and that it is a very positive experience in her life. Her family members, who continue to practice the Methodist faith, are less positive about her religion and feel somewhat uncomfortable with many of her beliefs.

In the last 2 years, Ms. L has developed a severe decubitus ulcer in her sacral area. Despite aggressive treatment, the wound has failed to heal and she has, in fact, become septic. Treatment has been complicated by the fact that Ms. L is extremely sensitive to a number of antibiotics, thus limiting the medical team's ability to effectively fight her infection. Ms. L's physician, Dr. P, feels that the only effective treatment at this point would be surgery. However, the process of surgically debriding the wound would result in Ms. L losing a significant amount of blood; thus she would require multiple transfusions. Therefore, on the basis of her religious beliefs, Ms. L has chosen to refuse surgery.

In the last two months, Ms. L's condition has dramatically worsened. Her infection has spread and her anemia—and overall medical condition—have deteriorated to the point that Dr. P feels it is likely she will die. Despite her weakened condition, Ms. L has remained coherent and quite able to articulate her views and concerns regarding her medical care. She continues to refuse any surgical interventions which would require blood transfusions; however, she has clearly stated that she does not want to die and continues to inquire about other possible medical treatment options. She has requested to be seen by a number of consultants from various medical specialties and has even sought assistance from her church in trying to locate other physicians in the area who might have alternative treatments to offer. Unfortunately, the opinions of all the other consultants have been essentially the same—unless she is willing to consent to surgery, and to the administration of necessary blood products, she

Cont. on page 6

Case Study

Cont. from page 5

will die as a result of her sepsis. Ms. L refuses to accept this and continues to insist on further treatment. She has consistently refused to discuss the possibility of hospice care and/or any limitations regarding her medical treatment including a DNR order.

Dr. P feels that he can do no more to help Ms. L and has requested that another physician assume her care. Ms. L, however, has refused to accept any other physician as her attending; although she is frustrated and angry with Dr. P, she feels she can trust him not to give her blood against her will. She fears that another physician might choose to override her wishes when she is no longer able to speak for herself. Dr. P has requested help from the ethics committee in dealing with this difficult situation.

Comments from a Bioethicist

From a practical ethical perspective, this case is one in which the physician finds himself in a "catch 22" — he's damned if he does and he's damned if he doesn't. He cannot abandon Ms. L without first at least attempting to provide her with a reasonable physician alternative. However, the likelihood of any physician becoming interested in the care of this patient during her last days is slim to none unless she is willing to try a hospice program. Since Ms. L refused to accept the serious nature of her terminal condition, she is not likely to become a candidate for hospice care. On the other hand, it appears that all the consultants who should have been consulted have been consulted and her prognosis is "death" with or without surgery.

This case, in my mind, raises the interesting question of psychological defense mechanisms and the obligation of the care providers and ethics consultants to attempt to "break through" those

defenses. Do those of us who are doing ethics consultations have an obligation to beat the patient over the head with "information" in order to validate an "informed refusal?" Does Ms. L really believe that she is dying? Or, is she making decisions in light of her previous life experience as a Jehovah's Witness who has been told on a number of other occasions that she needed blood transfusions or that she "would die?" Does she have the capacity to make this decision at this time? And whose obligation is it to assure that she does have the capacity?

First of all, I do think that care providers, including bioethics consultants, are responsible for assessing a patient's capacity for decision making prior to their agreement or disagreement with any specific patient decision. According to Appelbaum and Grisso, "Assessing Patients' Capacities to Consent to Treatment," (NEJM, 1988; 319:1635-1638), four patient abilities must be assessed, namely: 1) ability to render a choice; 2) ability to understand relevant information; 3) ability to appreciate the situation and its consequences; and 4) the ability for rational manipulation of information.

In this case, it seems that Ms. L can and has rendered a choice, understands relevant information (that is, she can tell you the nature of her situation and what she has been told about her prognosis), but if she consistently refuses to accept that prognosis claiming that, as a Jehovah's Witness, she has been given 'bad news' in the past and she is still alive, does she really appreciate this situation and the consequences of her choice? If she doesn't "appreciate" the situation, don't we have the additional obligation to assure that her choice, whether we agree with it or not, is a "valid" choice? Also, it would seem to me that if she believed that she were dying and that she stated that she was still willing to "die" based upon her religious beliefs and not upon her denial of the facts, I certainly would be more comfortable with this decision as an "informed refusal." The fact that she refuses surgery and continues to demand "further treatment," yet, consistently

refuses to discuss hospice care and/or any limitations of treatment has me confused at best and concerned at least. Consequently, I think it would be a good idea to try to get someone close to the patient to assess her "appreciation" of her situation, whether that be a religious colleague or a psychologist.

I am also concerned about Dr. P who "feels that he can do no more to help Ms. L." Is Dr. P familiar with end-of-life care in spite of the patient's lack of appreciation of her terminal condition? If she will not accept hospice placement, will she receive adequate palliation in her current setting? Is Dr. P the surgeon who has taken care of her wound in the past, but who feels less than adequate to care for a dying patient? If Dr. P is unable to provide adequate palliation and a dignified death for his patient, isn't it his obligation to resign from the case? If he did so, it would force the administration of the institution (Medical Director) to provide another physician for Ms. L, perhaps one more skilled in end-of-life care? Ms. L, in this day and age, should be assured that, were she to become incapable of making her own decisions, and with adequate documentation (durable power of attorney for health care and living will), that any physician would respect her religious beliefs and not transfuse her once she became incapable of making her own decisions. However, since her mother is her "next-of-kin," and since her mother does not share her religious beliefs, it behooves the ethics consultant to take advantage of this window of opportunity and be sure that this patient has adequate documentation of her blood refusal and any other limitations of therapy she might require.

It is not unusual for Ms. L to feel that she does not want to change physicians since Dr. P has respected her religious beliefs in the past and she does "trust" that he, at least, will not transfuse her. On the other hand, she cannot tie the hands of her physician by forcing him to provide less than adequate care to her. In some ways, neither Dr. P nor Ms. L are doing each other any good. Ms. L may be unable to get effective end-of-life care in spite of her condition, and

Dr. P, although responsible, well-intentioned and effective in the past, is now providing Ms. L with less than adequate end-of-life care.

Janicemarie K. Vinicky, PhD
Director, Medlantic Healthcare
Group Center for Ethics
Washington, D.C.

Comments from a Hospital Chaplain

As with many consultations where one has access only to limited information, this case raises additional questions beyond the information provided. Given the patient's religious faith as a Jehovah's Witness, I encourage contact with the following:

Hospital Liaison Committees Network
c/o Hospital Information
Services for Jehovah's Witnesses
25 Columbia Heights
Brooklyn, NY 11201
(718) 625-3600
(718) 596-2906 FAX

This is an organization that provides consultation support for health care providers involved with treating Jehovah's Witnesses through a nationwide network of Consultant Liaisons. By calling the above number, the Physician and/or health care provider may request access information related to the nearest Liaison Representative located in DC. This could prove helpful as the Liaison representatives are frequently more clinically astute than members from a local congregation. Upon review, the case raises the following questions for which I would suggest further amplification.

1. Given the patient's history of quadriplegia and potential for patient perceived reduced quality of life and the potential for clinical depression, was a psychiatric consult requested and evaluation completed?

Again, the Hospital Liaison may prove helpful in assessing the validity of the patient's current attitude toward treatment recommendations based solely upon religious belief and not contami-

nated by any latent desire to manipulate for self demise.

2. Given the patient's stated desire to live coupled with no understanding of the increased risks (associated with the continued refusal of transfused blood products), is there any possibility for surgical debriding? Even if incomplete, debridement may be sufficient for the purpose of improving the efficacy of a prescribed regimen of aggressive antibiotic therapy concomitant with aggressive therapy to manage negative side effects of such antibiotic therapy.

3. To what degree is the Physician and/or health care institution interested in pursuing the relationship with the patient in question?

If all options have truly been exhausted, there appears to be sufficient data to justify the current Physician's request to be withdrawn as attending. The Hospital Liaison Representative may prove to be of help with the patient accepting this. Also, the Liaison may prove helpful in locating another Physician to which the patient could be transferred for continued palliative treatment. It is the patient's right to refuse treatment which is in conflict with currently held beliefs; however, it is the Physician's right to refuse the provision of futile treatment. Ms. L's refusal to accept her current prognosis with attendant treatment recommendations renders further treatment (other than palliative) futile.

The Rev. Robert E. Steinke
Hospital Chaplain
Frederick Memorial Hospital

Ethics Committees and Consultants in Health Plans

As health insurance plans have moved from the business of simply providing insurance to the business of providing insurance and health care, there has been some speculation and some anecdotal information about their use of ethics committees or bioethicists. The "infamous" *New Republic* article¹ spoke disparagingly about the use of ethics consultants by managed care plans seeming to imply that if they used ethics consultants they did so primarily to justify their own decisions to cut costs or not to cover certain types of care. Yet, we really know very little about the use or lack of use of ethics committees and ethics consultants by health plans. A recent study conducted by researchers at the University of Maryland School of Law of senior medical directors at 34 out of the 52 Blue Cross Blue Shield Plans across the country, asked how many had established an ethics committee at the Plan level or used a bioethicist to consult with on Plan issues. The responses are listed below.

Of the 34 Plans, three (9%) indicated that they had established an ethics committee to deal with ethical issues in the treatment and coverage of Plan members. One had just recently done so, but another said they had a committee but the committee had stopped meeting. The respondent said the committee had been established in response to managed care issues arising in the state legislature. Of the remaining 31 Plans who said they had not established a committee, 4 said they were considering establishing such a committee. Of those 31, 14 said they would be interested in having such a committee in place and 16 said they would not. One did not respond. Of those who said they would not, some of the reasons given are listed below: "panel of in-house physicians act instead of any ethics committee and

Cont. on page 8

helps with any questions that come up or they consult an ethics committee at nearby institutions on a case by case basis”

“decisions needed are not ethical issues but contractual issues”

“long distance to get to meetings holds down number of any committees; one meeting will wipe out a whole day if must drive 250 miles one way”

“have not had ethical issues arise that need this type of expertise”

“able to reach individual members of [state] bioethics commission if the need arises”

“don’t think they are relevant to what we do”

“have discussed but have not found a need; our process with grievance committees and medical ombudsman works [well]”

“a standing committee . . . would not be utilized”

“ethics is [not] focused on the business of health care”

“Plan not really involved in ethical issues or decisions”

“ethics committees have no teeth, merely advise”

Eight of the Plans (24%) said they had used a bioethics consultant on at least one occasion. Of those 26 Plans who said they had not used a bioethicist, 15 (58%) said they would be interested in having a bioethicist available to advise them and 11 (42%) said they would not. Reasons why not were similar to those reasons for not being interested in having an ethics committee — they either already had a mechanism to deal with the issues or didn’t think an ethicist would be helpful to them.

¹ Shalit R. “When we were philosopher kings,” *The New Republic*, April 28, 1997.

RWJ END OF LIFE PROJECT

Both Maryland and the District of Columbia have applied for a grant from the Robert Wood Johnson Foundation under its initiative—Community-State Partnerships to Improve End of Life Care. Through this \$11.25 million program, the RWJ Foundation seeks to promote broad-based changes in public policies and practices that will improve care for dying Americans. The Foundation plans to fund states and communities that will work together toward developing systems of high-quality, comprehensive end-of-life care.

The Maryland proposal, initiated by the Office of the Attorney General, and headed up by staff and faculty at the Johns Hopkins Bioethics Institute brings together researchers at Hopkins and the University of Maryland as well as representatives from provider and consumer groups from around the state. The proposal builds on earlier data collection efforts funded by RWJ (see story, “Maryland Project on Care at the End of Life,” page 4.) and seeks to go beyond that effort to collect data regarding consumer experiences with end of life care, conducting public outreach and education, starting with regional town meetings and exploring electronic and other media for public dialogue; engaging in intensive efforts at provider education in palliative care, linked with efforts by attorneys to promote accurate understanding of Maryland law; conducting projects aimed at improving understanding and use of advance directives among the general population and those in health care facilities (nursing homes, in particular); exploring potential obstacles to adequate end of life care in managed care plans and developing a demonstration project that seeks to better integrate the recommendations of ethics committees with the guardianship process in end-of-life cases.

The District of Columbia proposal

is a joint effort of the Metropolitan Washington Bioethics Network, the District of Columbia Hospital Association, seven hospitals, three hospices, two home care programs, two nursing schools, two medical schools, several other providers, the D.C. Department of Health and a number of community groups. DCHA is serving as the lead agency for a planning grant which, if awarded, would provide funding for eight months during which the partners would plan a comprehensive program for later implementation. The planning grant has four goals:

(1) to develop strategies for professional education for physicians, nurses, social workers, clergy, and paraprofessionals at various points in their training: in academic programs, residency training programs, active practice, and continuing education. The focus would be to use research now underway at the Public Benefit Corporation/D.C. General Hospital and at Sibley Memorial Hospital to plan culturally sensitive materials which would help practitioners serve their seriously ill patients more fully;

(2) to build on research being conducted jointly by Hospice Care of D.C., The Washington Home & Hospice, and the VNA Hospice and by the American Hospice Foundation to learn about patient and family barriers to assessing hospice care and about patient satisfaction with hospice care, and to develop culturally appropriate public information messages to serve Washington’s diverse urban population;

(3) to assess current Medicaid and other reimbursement policies for hospice care to issue recommendations on how these policies could be modified to improve what is known about dying patients in the District of Columbia in order to plan more effective programs and services for this population.

(4) to look at other states' data collection efforts regarding end-of-life care and to develop an instrument to improve what is known about dying patients in the District of Columbia in order to plan more effective programs and services for this population.

The District's collaborators have determined that they will continue to meet every two weeks to take preliminary steps toward the goals listed above. New partners are welcome to join the group at any time. Background materials and a complete list of partners are available from Joan Lewis at DCHA.

The Foundation is expected to make its decisions about the recipients of the grants by the end of 1998. If funded, both jurisdictions plan to start their projects the first of next year.

DO YOU WORK IN AN "ETHICAL" ORGANIZATION?

The new focus in bioethics seems to be "organizational ethics." Yet, many people still seem to be confused about what organizational ethics is all about and certainly about how to achieve it. According to the draft report of the Society for Health and Human Values (SHHV) - Society for Bioethics Consultation (SBC) Task Force on Standards for Bioethics Consultation, "[t]he state of knowledge about organizational ethics consultation is in its infancy. Unlike clinical ethics consultation, there is a paucity of descriptive literature about the types of cases encountered and the various efforts to resolve them through consultation." The Task Force lists the types of issues that might arise in the context of organizational ethics and includes "billing practices, access to health care, financial incentives for clinicians to reduce utilization, restrictions on access to specialists, and marketing." Many of these issues have become

more salient in the era of managed care. Yet, these are primarily the technical issues that may arise for organizations in the new climate of health care cost containment, the report doesn't really address the broader question of what it takes to be an ethical organization and how we can help our health care institutions become more ethically conscious whether dealing with patient care issues or issues based on how the organization is run. The article by Evan DeRenzo, on page 1 in this issue of the newsletter, raises, I think, some of the more fundamental day to day issues that reflect on the ethics of an organization. These include such issues as how an organization treats its employees and how it relates to the surrounding community.

Recently, I came across a short article in a special edition of *Board Member*, a periodical for members of the National Center for Nonprofit Boards, entitled "Doing the Right Thing" that may be of help to those of us attempting to assist health care institutions become more ethically responsive organizations. The article, "Building Effective Ethics Programs," helps delineate the difference between an organization concerned with compliance and one concerned with ethics and values. It describes a compliance oriented institution as one that:

- ◆ Seeks to prevent civil and criminal misconduct
- ◆ Imposes external standards on behavior and evaluates decisions based on whether or not they satisfy the letter of the rule, reputation, law or policy
- ◆ Is motivated by the avoidance of penalties or punishments
- ◆ Uses legally driven reinforcements that emphasize restrictions—"what you can't do"

Conversely, the article describes an ethically or values driven institution as one that:

- ◆ Seeks to encourage responsible conduct.
- ◆ Builds on self-imposed standards and evaluates decisions based on whether or not they satisfy the organizations values and those of the decision-maker.
- ◆ Is motivated by self-actualization and improvement of the individual and the organization.
- ◆ Uses principal-driven reinforcements that emphasize personal responsibility—"what you should do."¹

Which type of institution do you work in?

Diane E. Hoffmann, J.D., M.S.
Professor of Law
University of Maryland
School of Law

¹"Building Effective Ethics Programs," 7 *Board Member* 8 (May, 1998).

CALENDAR OF EVENTS

JULY

29 -

August 1

WVNEC presents "Developing Core Competencies in Ethics Consultation," a Summer Intensive Program in Clinical Ethics at the Canaan Valley Resort in Davis, WV. The Program will focus on the recommendations of the Joint Task Force on Standards for Ethics Consultation and will introduce participants to these standards and assist them in developing the knowledge and skills to meet them. Program faculty include: Robert Arnold, MD, Co-Director of the Task Force, Jacqueline J. Glover, PhD, a Task Force Member, Alvin H. Moss, MD, and Sandra A. Price, JD. For more information or to reserve a space contact Cindy Jamison at (304) 293-7618.

AUGUST

17 - 22

The Center for Biomedical Ethics at the University of Virginia presents a unique six day course of study for health care professionals from hospitals and other health care institutions. The course is designed to facilitate or strengthen the implementation of an ethics program within these institutions. Developing Hospital Ethics Programs (DHEP), encourages discussion of the theoretical and practical aspects of a working program in patient care and organizational ethics. This program is also being developed in response to a growing concern over the implications of the JCAHO's 1995 requirement that health care organizations implement an organization ethics function. Dr. Spencer, Director of the Program, is inviting up to 15 previous DHEP participants to attend the session. Please call Ann Mills at (804) 982-3978 if you are a previous Fellow and require more information or would like to receive information about this program.

SEPTEMBER

17

University of Maryland Medical System Medical Humanities Hour. Dr. David Flood and Dr. Ronda Sorricelli from Allegheny University of the Health Sciences will speak on "The Illness Experience: A View From The Visual Arts." 4:30 - 5:30 p.m. Shock Trauma Auditorium. For more information call (410) 706-6250.

23

Sixth Annual Henry D. Ecker Lecture at the Washington Hospital Center. The speaker will be Ira Byock, MD, Director, Palliative Care Service, Missoula Montana. 12:00 noon. For more information call Sue Edwards at 202-877-6211.

25 - 26

The National Conference on Organization Ethics and Health Care will be held at the Jordan Hall Conference Center in Charlottesville, Virginia. Topics will include legal issues, organization ethics and business ethics for health care organizations. The conference is expected to draw a number of scholars from the academic, legal and health care provider communities. For information on the conference, please call (804) 924-5974.

OCTOBER

- 8 University of Maryland Medical System Medical Humanities Hour. Arthur Caplan, PhD, Director, Center for Bioethics, University of Pennsylvania, will speak on "Should We Design our Descendants? Reproductive Technologies and the New Genetics," 4:30 - 5:30 p.m. Shock Trauma Auditorium. For more information call (410) 706-6250.
- 30 The Maryland Health Care Ethics Committee Network will hold its first annual meeting and conference on "Sustaining the Life of you Ethics Committee." The conference will be held at the Bons Secours Spiritual Center in Marriottsville, MD. For more information contact Anne O'Neil at 410-706-4485.

NOVEMBER

- 4 - 5 The Virginia Bioethics Network and the Center for Biomedical Ethics will co-sponsor the workshop "Ethics in Health Care Institutions: New Issues, Controversies, and Practical Considerations." The workshop will address current legal changes which are expected to affect ethics committees, and consensus and mediation issues which may occur in ethics consultations. Presenters will explore the ramifications of the SHHV-SBC task force report and a panel of ethics committee members will discuss their work in developing organizational ethics committees. For more information call 804-982-3978.
- 12 University of Maryland Medical System Medical Humanities Hour. David Barnard, PhD, University Professor and Chair, Department of Humanities, Pennsylvania State University College of Medicine, Hershey, PA will speak on "Ambivalence, Uncertainty, and Hope: Complexities in the Transition from Curative Treatment to Palliative Care." 4:30 - 5:30 p.m. Shock Trauma Auditorium. For more information call (410) 706-6250.

DECEMBER

- 3 University of Maryland Medical System Medical Humanities Hour. Marion Danis, MD, Senior Staff Bioethicist National Institutes of Health will speak on "Advance Directives: Are They Working?" 4:30 - 5:30 p.m. Shock Trauma Auditorium. For more information call (410) 706-6250.
- 11 University of Maryland School of Law's Law & Health Care Program will hold its fall conference on "Death in America." Speakers will include Robert Burt, Professor, Yale Law School; Anne Wilkinson, Center to Improve Care of the Dying; Pat Grady, National Institute of Nursing Research; Alan Meisel, Professor, University of Pittsburgh School of Law; Dewitt C. Baldwin, AMA.

