Mid-Atlantic Ethics Committee Newsletter, Fall 1993

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THE ROLE OF COMFORT CARE AND PHYSICIAN ASSISTED SUICIDE IN THE SEARCH FOR A DIGNIFIED DEATH

One of the most pressing challenges facing modern medicine is to find a way to allow terminally ill and intractably suffering patients to die with as much dignity, control, and comfort as possible. Despite comprehensive efforts to provide pain relief and emotional support at the end of life, there unfortunately remain instances in which incurably ill patients suffer intolerably before their deaths. Though it is rare, such irreversibly suffering patients are increasingly turning to their physicians with requests for relief, not only in terms of better pain management and comfort care measures, but sometimes with specific requests to help them end their lives. For many physicians, to assist such patients in escaping from their unrelenting suffering seems a humane and compassionate response, yet they are reluctant to do so for a variety of professional, legal, and moral reasons. The traditional aims of medicine to relieve suffering and also to preserve life are clearly at odds in such instances. The agonizing clinical decisions posed by this tension in the modern hospital setting require careful and nuanced balancing of these essential aims, and the medical profession is now engaged in a passionate debate as to how it should respond to this complex dilemma.

A majority of the American public has supported the right to a physician's assistance in dying in every available public opinion survey taken over the last four decades; the support for such a right is highest among the elderly.

Letter From the Editor

In this issue we focus almost exclusively on the topic of physician assisted suicide. The lead article is a significant piece on the subject by Dr. Michael Kligman, a psychiatrist and Director of the Consultation-Liaison Psychiatry Service at the University of Virginia Health Sciences Center. A second article discusses the legal status of physician assisted suicide in Maryland, D.C. and Virginia and summarizes proposed legislation in Maryland to criminalize the action. Our case study involves the withholding of antibiotics from a nursing home patient. Please let us know if you have ideas for future issues.

Diane E. Hoffmann

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NETWORK NEWS

Baltimore Area Ethics Committee Network (BAECN)

The next BAECN Meeting will be held on November 11th from 4:30 - 6:30 p.m. at MANOR CARE RUXTON, 7001 N. Charles Street. The topic for discussion is the proposed Maryland Legislation that would criminalize physician assisted suicide. The discussion of the proposal will be led by a panel including:

Lewis Breschi, MD, Franklin Square Hospital
Ellen Callegary, JD, Maryland Chapter of the ACLU
Robert Roca, MD, specializing in psychiatry
George Taler, MD, specializing in geriatrics
Ralph White, PhD, resident of Broadmead Retirement Community

Also, at the September meeting of the NETWORK, attendees expressed interest in the establishment of a repository for institutional policies on various issues of relevance to ethics committees, e.g., withholding and withdrawal of life sustaining treatment, DNR orders, etc. If you would be willing to share your policies with other institutions, please call 706-7239 for more information.

Washington Metropolitan Bioethics Network (WMBN)

The November meeting of the Network will be held on Tuesday, November 16th from 4:00 - 6:00 p.m. at the Hospital for Sick Children. Carolyn Harris, J.D., R.N. is organizing the program about pediatric long term care issues. There is no meeting scheduled for December. If you would like to host or have an idea for a topic for 1994 call Joan Lewis at (202) 682-1581.

ANNOUNCING...

VIRGINIA BIOETHICS CENTER COURSE

The University of Virginia's Center for Biomedical Ethics will next offer its course, Developing Hospital Ethics Programs (DHEP), from March 14th through March 19th, 1994, at the University of Virginia in Charlottesville.

DHEP was originally begun in 1990 to help health care institutions develop and/or strengthen their individual institutional ethics programs. The Program helps institutions develop an ethics educational program for staff and patients, better conduct ethics consultations, and network with other ethics programs.

The DHEP course is primarily a training session for two or more professionals from each participating institution who are interested in acting as "ethics resource persons" during the development and strengthening of their institution's ethics program. Health care professionals from over 35 hospitals in seven states have participated in previous DHEP courses.

For more information contact Dr. Edward Spencer at (804) 924-5974.

M.A. PROGRAM IN CLINICAL ETHICS

The University of Virginia is now receiving applications for its M.A. program in Clinical Ethics which will begin its fourth year in Fall, 1994. Applicants must be members of a profession (MD, RN, JD, MSW, MDiv, etc.), specially, or discipline contributing to clinical ethics, or exceptional candidates with equivalent life or work experience. The program's goal is to prepare persons to be leaders of clinical ethics programs in health care institutions. Applications are due by Feb. 15 of each year. Write: James F. Childress, Ph.D., Chairman, Department of Religious Studies, University of Virginia, Charlottesville, VA 22903.
The Role of Comfort Care and Physician Assisted Suicide
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Among physicians, those working in geriatric, oncologic, and hospice settings voice the strongest support for legalizing the carefully regulated practice of physician-assisted suicide. There is good reason for this. Those who have had the opportunity to frequently witness death as it is currently played out in the modern era of high-technology medicine recognize that there comes a time in the dying process when the arrival of death is an unequivocal blessing, a merciful and welcome end to a tragic and often degrading experience. This remains true even in the most humane and enlightened hospice settings, where comfort care and psychological support have been maximized.

Many people understandably do not wish to experience excessive periods of severe pain and frailty at the end of their lives, and most agree with the proposition that “some things are worse than death”. Some have witnessed their loved ones linger in helpless dependency, waiting and sometimes actively hoping for death. Modern technological medicine has greatly increased the likelihood of our spending our declining years or months irreversibly incapacitated, permanently dependent on artificial means of life support, even unconscious for extended periods. Some people and their loved ones say they can find acceptance and meaning under these circumstances, but many others actively express dread at the thought of such a fate. People now routinely fear that their physicians will either overtreat them with life-prolonging technology long after a return of meaningful function is possible, or abandon them to their suffering when they badly need continued attention directed at control of symptoms and emotional support.

Anxiety and depression are common as people become aware that they are approaching their own death, both because of the physical threats of dying and because of the challenge death presents to our sense of self-worth and self-coherence. The most frightening aspect of death is often not the physical pain, but the prospect of losing control and independence, and dying in what for many seems an undignified, helpless, and ultimately unacceptable condition. People facing death under these circumstances sometimes become preoccupied with such fears, unable to think of anything but their continuing decline, their losses and failures, the prospect of continued pain and a pervasive sense of indignity and futility. The tragic suffering associated with lingering and difficult deaths leads many people to question their sense of self-worth, to feel that they can no longer be worthy human beings in the eyes of others, or to feel themselves a burden on their families or society.

It is not necessarily indicative of major depression or other psychiatric illness for incurably ill persons to desire relief from a prolonged, personally intolerable dying process through hastening or otherwise controlling the circumstances of their own death. In other contexts, severe and pervasive hopelessness and despair generally signal the presence of a treatable depression, which can respond dramatically to antidepressant medication and psychotherapy. But for some dying individuals, a certain degree of hopelessness and despair, and even the wish for relief from suffering through death, are distressing but understandable reactions to the harrowing experience of a painful and debilitating terminal illness. Certainly every attempt should be made to bring psychological and spiritual comfort to these persons, including careful assessment for and treatment of depression when it is present. But the presence of depression is ultimately relevant only if it is distorting rational decisionmaking, and if it is reversible in a way that would substantially alter the degree of suffering being experienced and, consequently, the wishes of the patient. It is simply untrue that the presence of loving family members, adequate pain relief, antidepressant medication, and other measures are always capable of relieving the powerful sense of futility and indignity, and the accompanying wish for relief through death, experienced by some dying patients.

Historically, the physician’s broad commitment to preserve life, embodied in the Hippocratic oath, has been reflexively translated into an unthinking struggle to vanquish death at all costs, often with little regard for the subjective experience or wishes of the patient. It is now plain that rigid adherence to this ancient dictum sometimes results in inhumane and indefensible practices. Though it is not an easy or comfortable process, thoughtful physicians are beginning to rethink these issues with a broader awareness of the importance of patient autonomy, and a recognition of the limits of medicine’s curative powers. Medicine has traditionally seen death as a failure. Doctors, patients, and families have often colluded in denying the reality of an approaching death. But many observers both within and outside of organized medicine are now calling for its practitioners to fully acknowledge the irreversible suffering and prolonged debilitation inherent in many illnesses, and to acknowledge death as a natural part of life’s continuum rather than continuing to treat it as another obstacle to be overcome. Doctors must acknowledge the increasing role that medical technology plays in setting patients up for what many now consider to be an unacceptable way of dying. As death becomes unavoidable, medical care should allow the patient to die in a setting of his or her own choosing, as free as possible from pain and other burdensome symptoms, and with the optimal psychological and spiritual support of family and friends. Life-prolonging interventions should be used only when they are likely to produce a reasonable quality of life or level of function, as determined by the wishes and life goals of the patient.

Unfortunately, few physicians are skilled in the adequate use of narcotic analgesia or other measures they can
invasive and painful efforts at diagnosis and cure despite the patients objections, and later by the doctors explicit discounting of his patients clear and repeated requests for assistance in dying. The very fact that their doctor is denying them relief by refusing to provide aid-in-dying can be perceived by patients as a bitter injustice. An awareness of the indignity of being ignored in this way, of essentially being told that they must endure what they clearly do not wish to endure, sometimes becomes the overriding preoccupation of patients facing death in the modern hospital setting. In those instances where the prior application of high-technology medical interventions has helped bring the patient to a state of intolerable suffering, it seems especially unconscionable that physicians sometimes walk away, denying that medicine can do anything to help in the patients plight.

Quill advocates that assisted suicide for the terminally ill be provided only as a last resort, after all other comfort care options have been exhausted. It should remain, in his view, a tragic and rare experience. In order to safeguard against the abuse of physician assisted suicide were it to be legalized, many versions of the essential preconditions which should first be met have been proposed. All of these proposals share two fundamental criteria: first, that an adequate trial of other means to relieve suffering has been tried and failed; and second, that adequate assurance exists that the patient is making a voluntary, informed and rational decision. In my view, the criterion of voluntariness is of critical importance. The patient must clearly and repeatedly, of his or her own free will and initiative, request to die rather than continue suffering. If rigorous adherence to the criterion of voluntariness of this sort can be achieved through procedural and legal safeguards, and emphasized as the most central tenet justifying the practice of physician assisted suicide, then I believe the line can be effectively held against the feared "slippery slope" leading to the unwished-for taking of life from those deemed to be unworthy or otherwise burdensome to society.

Nearly as important as the criterion of voluntariness is the requirement that serious efforts at providing relief of pain, psychological support, treatment of depression, and other comfort care measures have been attempted. It has been suggested that doctors would have less incentive to become proficient at providing such skilled comfort care if the "out" of a quick, controlled death were too readily available. If documentation of such efforts was made a strict prerequisite to the consideration of physician assisted suicide, then the opposite effect is more likely, with doctors becoming both more skilled at, and more likely to employ, such measures.

In order to respond to patients' legitimate needs without endangering the vulnerable or disenfranchised, Quill and others advocate legalizing physician assisted suicide, in which the final act causing death is left solely in the hands of the patient, while continuing to forbid voluntary active euthanasia (VAE), in which the physician both provides the means and carries out the final act. In the former, the patient has added control over the time and setting of death, as well as the benefit of often significant psychological relief in the knowledge that a means of escape from suffering is now in their possession. The time-period before a controlled death can provide an opportunity for a rich and meaningful goodbye between patient, family, and caregivers. In individual cases where appropriate criteria have been rigorously met, and death clearly represents a humane and merciful end to prolonged suffering, most ethicists now agree that there is no significant moral distinction between allowing to die (either by withholding life-sustaining treatment or providing the means by which patients can take their own lives), and actually causing death. Both physician assisted suicide and VAE involve the active facilitation of a wished-for death. In assisted suicide, however, the final act is taken by the patient, and the risk of subtle coercion from doctors, family members, or others is thus greatly reduced. In voluntary active euthanasia, the
physician initiates the final act, making the possibility of error, coercion, or abuse much more likely. Though there are clearly individual instances in which VAE is humane and morally appropriate, I agree with Quill that its greater potential for abuse makes the question of legalization far more difficult and ambiguous.

The case against physician assisted suicide and VAE is based mainly on the implications of such practices for public policy, and their potential effect on the moral integrity of the medical profession. Some hold that the oldest and most central tradition of medicine is the duty to preserve life, and that practitioners of the “Healing Art” should therefore never become “killers”. They further state that an ethical society has a compelling interest in maintaining the general prohibition against “killing” through its laws and institutions. But to frame these complicated issues in such sweeping terms is both simplistic and misleading. There comes a time for some competent patients when death is clearly, in their own minds and consistent with their deepest values, the best of many bad options. If a patient wishes to die is clear, unwavering, and understandable, then the intent to help him or her carry out that rational wish is not best described as “killing” the patient, with all the connotations of unwanted taking of life associated with that term. Physicians must come to terms with the fact that sometimes all of the options available are undesirable, with death being the least of several unavoidable evils. Medicine in the contemporary era is squarely confronting the tension between remaining true to its historical roots and traditions, and trying to respond sensitively and effectively to the changing needs and ethical values of the society in which it is practiced. Doctors sometimes fear they may be “playing God” by assisting patients in a wished-for suicide, even when they understand the request to be reasonable and rational under the circumstances. It is difficult to see how essentially dictating to patients that they must endure unwanted-for debility and indignity, by refusing to provide them with aid-in-dying, implies any less willingness to assume the Divine role.

Some fear that no matter how humane the intent, a public policy permitting assisted death would inevitably lead to deleterious social consequences. The “slippery slope” argument asserts that well designed policies which minimize risks of abuse would eventually be eroded to allow more permissive standards for physician assisted suicide, ultimately resulting in the subtle coercion of the powerless to choose death rather than become a burden on their families or society. The specter has been raised that in times of financial crisis, cost-benefit considerations could lead to practices such as culturally encouraged suicide and early euthanasia for vulnerable groups such as the rapidly growing elderly, demented population. But such extreme practices are a far cry from the humane response to repeated, voluntary requests being discussed here. With strict attention to the criterion of voluntariness, the vulnerable would not be exposed to any new risks. Indeed, with careful legal and procedural safeguards in place, and the open scrutiny and discussion which would result from the legalization of physician assisted suicide, many believe that there would be fewer abuses of the vulnerable than are probably now occurring under the present system of unregulated and undocumented end-of-life decision-making.

Another objection commonly raised against the legalization of physician assisted suicide is that it would serve to undermine the trust patients have in their physicians. For a significant segment of society, it is clear that physician involvement in assisted suicide would be welcomed, not feared. At present, physician-patient trust is compromised by the widespread concern that doctors try too hard to keep dying patients alive. While relatively few patients would actually seek out help through physician assisted suicide if stricken with a debilitating illness, a substantial number would take solace in knowing that they could request and receive such assistance should the need arise. No one can accurately predict how the legalization of physician assisted suicide would affect the complex character of physician-patient trust in the rapidly changing context of modern medical practice. In my view such a step would be more likely to help reclaim some of the public trust in physicians which has already been badly eroded. Doctors can best serve their patients, and ultimately earn their trust, by respecting their desire for autonomy, dignity, and quality, not only in life, but with regard to the process of dying itself.

How should a physician respond to a request for assistance in dying? Most such requests represent opportunities for improved symptom control and other efforts at more effective comfort care. If the request is taken seriously and explored by the doctor, rather than awkwardly dismissed without discussion as too often occurs now, the door may be opened to taking steps towards better pain management or the treatment of depression. If a competent, incurably ill patient continues to yearn for death despite comprehensive efforts to provide comfort care, then a range of options should be discussed. These presently should include the patients right to refuse life-prolonging medical interventions, including the right to refuse artificial feeding and hydration. In the event that physician-assisted suicide were legalized, explicit discussion of the physicians willingness to undertake such a course should occur. Of course, those doctors for whom such an undertaking would conflict with their fundamental beliefs and values cannot be forced to offer such services; however, the transfer of care to another physician should then be pursued.

Physicians who compassionately respond to their patients requests for aid-in-dying at present place themselves in some professional and legal jeopardy. They rarely consult with colleagues, and they and others often leave the patient to carry out the final

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act alone, so as to avoid being implicated in an illegal act. Explicit, procedural and legal safeguards can bring these hidden and poorly controlled practices into the light of rational scrutiny and open debate. I agree with Quill and others that there is more risk to vulnerable patients and the integrity of the medical profession in such hidden practices than there would be in a more open process, restricted to competent patients who meet carefully defined criteria.

The process of translating the fundamental safeguards necessary to prevent abuses into specific and workable public policy will indeed be challenging. A physicians too-ready acceptance of a patients request, exemplified in the practices of Dr. Kevorkian, could be justly characterized as glib encouragement to commit suicide; on the other hand, it is important not to make the safeguarding procedures too cumbersome, so as not to force dying patients to have to "beg" for assistance. It is never possible to know with absolute certainty that everything has been done to alleviate pain or depression, or that a patient wouldn't change their mind if only one were to wait a little bit longer. Not every patient should have to go before a judge and jury to obtain relief. However, many believe that some type of official regulatory bodies should be constituted to review these cases, to ensure that core safeguards are rigorously adhered to.

The risks of undertaking change are real, and the ultimate emotional and social effects of changing these ancient prohibitions are impossible to predict. But many regard the current status quo of the dying process in modern America, with its too frequent scenarios of lingering and unwanted misery often brought about by the application of high-technology medicine, to be inhumane and unacceptable. Both physicians and non-physicians alike believe that change is needed. Let us proceed with caution, but let us proceed—to do otherwise is to turn our backs as medical professionals on the tragic suffering which we have sometimes unintentionally helped to create, and which it is within our power and responsibility to try to help alleviate. We must not abandon incurably ill patients to their suffering. Fear for our own reputations or the integrity of the medical profession seem abstract concerns when one is faced with the immediate and painful pleas of a suffering, incurably ill patient seeking to hasten an inevitable death which will clearly bring welcome relief. These patients legitimate needs should not go ignored because of our reluctance or inability to reshape policy in this complex and contentious area.

He concluded that while the new Maryland Health Care Decisions Act specifically disclaims any approval for euthanasia or mercy killing, it is not clear that a physician could be successfully prosecuted under Maryland law if he/she provides a patient with the means to commit suicide.

Dr. Kevorkian has gained a great deal of notoriety for the assistance he gives to terminally ill patients who wish to commit suicide. He provides patients with "suicide machines" such as carbon monoxide masks or lethal injections that can end the patients' life quickly and painlessly. In response to Dr. Kevorkian's actions the Michigan legislature passed an emergency act banning such assistance. Despite this new law, Dr. Kevorkian has continued to provide assistance and currently faces prosecution for his role in the seventh suicide in which he allegedly played a role.

At least thirty-five states have enacted statutes banning suicide assistance and five states have done so through case law. For those states that do not have legislation which governs this issue, it is debatable whether or not a physician who assists in a suicide can be prosecuted and if so for what crime. Maryland, Virginia and Washington, D.C. are among the states whose legislatures fail to address this issue.

This gap in legislation motivated the recent Opinion by the Maryland Attorney General. The Attorney General's Opinion indicates that suicide may remain a common law crime in Maryland, although there are no longer penalties imposed on a deceased's estate or on a person who fails in their suicide attempt. The Opinion cites other states that continue to view suicide as a common law crime despite the fact that it is no longer a punishable crime. If a Maryland court concluded that suicide is a common law crime, assisting in suicide would also constitute a common law crime. As yet, the Maryland courts have not been confronted with the issue and it is not clear how they would decide.

If assisted suicide is not considered a common law crime, the Attorney

THE LEGAL STATUS OF PHYSICIAN-ASSISTED SUICIDE IN MARYLAND, D.C. & VIRGINIA

If Dr. Kevorkian came to Maryland, D.C. or Virginia, could he be successfully prosecuted for assisted suicide? This is not an ethical question as to whether he should be prosecuted but rather a question as to the status of the law regarding assisted suicide in each of the three jurisdictions. It was a question that the Maryland Attorney General attempted to answer in an Opinion issued on September 9, 1993.

Submitted by
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General’s Opinion states that it is unlikely that any alternative means of prosecution would succeed. Any prosecution for homicide will almost certainly fail by definition since the deceased actually took their own life. A prosecution under reckless endangerment would also be difficult since a physician’s actions under the above circumstances is not likely to meet the requirement that it be “careless and heedless.”

The Attorney General’s Opinion also addressed some of the ethical considerations involved in physician-assisted suicide. Some ethicists have expressed concern about the possibility that allowing for physician-assisted deaths may lead those who are depressed or frightened to turn to suicide rather than seek help. There is also the fear that some may become desensitized to the killing of others, leading to frightening possibilities for the future.

The Washington, D.C. Code does not have a statute that addresses assisted suicide as a distinct crime but does refer to assisted suicide as a crime in the Natural Death Act. The Natural Death Act statute states that “the withholding or withdrawal of life sustaining procedures from a qualified patient in accordance with the provisions of this subchapter shall not, for any purpose, constitute the crime of assisting suicide.” D.C. Code Ann. §6428 (1992). Clearly, physician-assisted suicide is regarded as a crime in Washington, D.C., however, the penalties for committing such a crime are not clear either in the criminal statutes or in the case law.

In Virginia there is also evidence that the state does not condone physician-assisted suicide, but again the penalties for committing this “crime” are not clear. The Virginia Health Care Decisions Act specifically prohibits mercy killing or euthanasia. The Act states that “nothing in this article shall be construed to condone, authorize, or approve mercy killing or euthanasia, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying.” Va. Code Ann. §54.1 (Michie 1993). Also in a recent case in Virginia, the Supreme Court of Virginia held that suicide is still considered a common law crime, although it is no longer a punishable one. Wackwitz v. Gaston, 418 S.E.2d 861 (1992). Therefore, a successful prosecution for assisting in the commission of suicide is questionable.

All three states have neglected to enact statutes that prohibit physician-assisted suicide. It would appear, however, that this does not signify approval for physician-assisted suicide because of the language found in each state’s statute authorizing withholding or withdrawal of life-sustaining treatment under certain circumstances. It is certain that if these states wish to make their policy with regard to physician-assisted suicide clear, legislation should be enacted either protecting or prohibiting physicians from taking such action.

Based on this reasoning, the Maryland Attorney General’s Office has proposed legislation in Maryland that would criminalize physician-assisted suicide. The legislation states that those who assist an individual in committing suicide will be guilty of a felony punishable by up to $10,000 and/or up to three years in prison. There are exceptions for a practitioner who withholds life-sustaining treatment pursuant to the Maryland Health Care Decisions Act or “in accordance with generally accepted medical practice and without intending to cause death, prescribes, dispenses, or administers medication or performs a procedure to relieve an individual’s pain or discomfort, even if the medication or procedure might directly or indirectly hasten the individual’s death or increase the risk of the individual’s death.”

The proposed statute would also provide for injunctive relief against a person who “is reasonably believed to be about to violate” or who is in the course of violating the statute. The injunction must be brought by a person with a close relationship to the person who would commit suicide or by the State’s Attorney’s Office or the Attorney General’s Office. Those having the necessary relationship would include a parent, spouse, child or sibling, the individual’s health care professional, or the guardian of the individual. The proposed legislation has not yet been introduced into the legislation, so chances for successful passage are uncertain.

Some have questioned whether a statute criminalizing assisted suicide would be constitutional. In his September 9th Opinion, the Maryland Attorney General concluded that a constitutional attack against such a statute would not be successful. Although a citizen may have a liberty interest in having the ability to commit suicide, the state can override that interest if they show a rational basis for enacting such a statute. The rational basis underlying a statute banning physicians from assisting in suicides would be the state’s general interest in preserving life and the medical professions’ interest in maintaining rather than destroying life.

At this time, according to Choice in Dying, “seven states have bills pending that would change their assisted suicide laws. Georgia, Illinois, Ohio and South Carolina are considering bills to criminalize assisting a suicide, while Maine, New Hampshire and Vermont are considering enacting statutes to legalize physician-assisted suicide. This state of affairs reflects our country’s thorough lack of consensus on the issue of assisted suicide.”

1. 78 Opinions of the Attorney General (1993) (Opinion No. 93-036 (September 8, 1993)).
5. Celocruz supra at 377.
7. Attorney General’s Opinion, supra at 8.

Submitted by
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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 in the region 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 Consultation in a Maryland Nursing Home

PRESENTATION: THE CASE OF MRS. GREEN

An 86-year-old woman, Mrs. Green, was admitted to a nursing home because of progressive dementia due to Alzheimer’s Disease. She had never made any advance directives and was incapable of doing so. She had significant tardive dyskinesia secondary to previous administration of psychotropic medications. She was also bedbound, totally dependent in her activities of daily living, and fed via a gastrostomy tube. She was on Dilantin for a seizure disorder. She was alert, but only made some incoherent noises in response to questions. Her family stated that while she had never made an advance directive, she had previously expressed her wish that her life not be prolonged indefinitely by extraordinary measures. After several years in the facility with little change, they felt that her persistent bedbound state and limited cognitive function were not consistent with a desirable quality of life. They requested that her physician treat her as a terminal patient, and discontinue any aggressive medical interventions. Her physician agreed not to implement antibiotics, but did not think that she was terminal. A consultant physician agreed that she was not terminal, and that not using any antibiotics would be appropriate. About 6 months later, she developed an abscess in her left inner thigh. Her attending physician insisted that antibiotics should be used to treat this, since she was not terminal. At the same time, the family found out that the physician had been maintaining her on a long-term prophylactic dose of a urinary anti-infective. The family requested a change in physician. The new physician agreed not to use antibiotics, and was prepared to treat her as terminally ill, but the medical director and other physicians in the nursing home met and decided that it was not appropriate to manage her case in this way. The patient’s family requests an ethics committee consult. What do you advise?

Case Discussion: Comments From a Nursing Home Medical Director

Mrs. G was in the advanced stages of a progressive, irreversible condition. While she was alert, she was totally dependent and bedbound. There was no way of ascertaining if she was aware of her surroundings.

This case illustrates the difficulties of deciding on the appropriateness of treatment when a person is not terminal, but has potentially treatable conditions which could hasten death if they are not treated. It also illustrates the difficulties of absolute prohibitions of a particular form of treatment, as opposed to treatment in a given situation.

The family claimed that she had certain wishes regarding the use of extraordinary measures. Because these had never been documented, they could at best apply a substituted judgment standard in making decisions for her. If this did not seem to apply, then a “best interests” standard would apply.

This case is also complicated by the difficulties in defining “terminal,” and the problems of laws limiting treatment decisions to the “terminal” situation. In Mrs. G’s case, her degenerative condition was advanced but her death was not necessarily imminent. Many individuals are not necessarily terminal but nevertheless have little hope for recovery or improvement. Various state laws have been, and should continue to be, revised to allow for more flexible decision making in cases other than terminal conditions. If such a law had been in effect at the time this case was being managed, it would not have been necessary to argue over whether the condition was terminal. Instead, efforts could have been focused on prospects for further general decline or improvement, and the likelihood of any intervention or life-sustaining treatments to improve the condition or restore some quality of life in the face of an inevitably progressive condition.

The physician may have been deceptive in the way he used prophylactic anti-infectives to prevent urinary tract infections. There had been an agreement not to use antibiotics, in anticipation of an infection that could eventually lead to a terminal state. While an anti-infective is technically not an antibiotic, the basic spirit of the agreement was not being honored. This decision should have been discussed openly with the family.

The occurrence of the abscess raises the issue of the absolute prohibition of various treatments. The typical prohibition against antibiotic use is intended to prevent their use to aggressively treat a significant systemic infection (pneumonia, septic shock) that would otherwise progress to probable death. However, a localized abscess is not exactly the same as a major pneumonia or septic shock. In some cases, managing the abscess could be considered a comfort measure. In any event, a week’s course of
antibiotics probably would have helped resolve the abscess but was not likely to significantly prolong this patient's life.

A facility ethics committee should review the case and consider the various evidence. If the attending physician does not agree with the wishes of a surrogate decision maker, there should be a mechanism for changing physicians. The ethics committee is an appropriate forum for all sides -- facility administration, medical director, other physicians, family, resident -- to present their perspectives and reasons. Other physicians should not simply have the prerogative to block an appropriately agreed upon course of action.

In this case, an ethics committee could help all parties review the case and better understand each others' positions. Often, disagreements occur because of different starting premises. The various parties argue over conclusions but may not ever take the time to discuss the underlying premises that led them to those conclusions. The ethics committee can play an important role in getting those parties to focus first on these starting premises. If the parties cannot agree on the underlying premises, then the ethics committee should strongly encourage flexible decision making, rather than a decision simply imposed by those with the authority to do so. The primary emphasis should be patient-centered, i.e., the potential benefit or drawbacks of the proposed interventions. Often, the parties could agree on the best clinical course, but one or more of them may fear the consequences of making a particular decision, based on legal or other considerations. Thus, the parties should be encouraged to delay considering their reasons not to do what may be in a person's interest (e.g., the legal implications). In this way, if it can be agreed as to what is the best thing ethically and clinically, it may then be possible to address the legal complications constructively, in a way that satisfies all the parties at possible risk.

If the facility does not agree with limitations on care, the family should have the option to move the resident to another facility. Although not all circumstances can be anticipated, a facility's policies about limiting or withdrawing treatments should be clarified upon admission, rather than created on an ad hoc basis as cases arise. The ethics committee should play a major role in such policy clarification.

Submitted by
Steve Levenson, M.D.
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Asbury Methodist Village
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Case Discussion:
Comments From a Nurse Administrator

The description of the condition of Mrs. Green is a common phenomenon in nursing homes. Dementia and dementia-related problems constitute the major reasons for nursing home admissions.

We know that dementia decline is progressive and typically long. At each observable step in diminishment of functional and behavioral aptitude, a new set of decisions must be made about appropriate and humane care and new coping mechanisms must be established by care givers in the home, in the nursing home, and in the medical community. Care plans usually assure at a minimum, nutritional support, safety, and maintenance of human dignity. As long as the person is mobile, able to eat, and free from serious illness, cognitive decline and behavioral impairments can be accommodated and adaptations made. However, as the person begins to refuse food and fluids, and/or develops aberrant behaviors and physical problems that must be treated or supported by mechanical or pharmacological intervention in the face of further functional decline, the issues of burden and coping, appropriate and humane care pierce hearts and consciences again and again. Care plans must reflect the changes and anticipate appropriate decision points based on careful analysis of the resident's life and moral expectations.

In the case of Mrs. Green, multiple pharmacological and technical intervention decisions have already been made. Her condition has "stabilized" in a "persistent bedbound state and limited cognitive function". This state is described by the family as one that is "not consistent with a desirable quality of life". And the family adds the penetrating phrase that "she [Mrs. Green] had previously expressed her wish that her life not be prolonged indefinitely by extraordinary measures".

The family requests that Mrs. Green be treated as terminal and that her physician "discontinue any aggressive medical interventions" including antibiotic therapy. The family's role as surrogates via their request for limiting medical interventions is tested when Mrs. Green develops an abscess in her left inner thigh. The family and the medical community at this facility reach an impasse and the situation is sent to the ethics committee.

ETHICAL ELEMENTS/MORAL ANALYSIS

The task of the ethics committee in this case is to identify and examine the critical pieces that must be ferreted out in order to facilitate a plan of care based on what is right for Mrs. Green. The important elements in this case include: articulating the major issues; probing the players; looking at the law; and perusing the day to day life of Mrs. Green.

Articulating the Major Issues

The case raises the following three questions: 1) does the family possess the right to speak on behalf of Mrs. Green, i.e. can they act as her surrogates; 2) when is a person considered to be in a "terminal condition" and 3) what in this case is considered aggressive medical intervention. These issues may be described as generic issues and should be addressed alongside some of the other more specific issues presented.

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Probing the Players
Ethics committees, in part because of their diverse membership, possess the advantage of being able to examine a situation in relation to all of the major players in a unique way (Hoffmann, 1991). Complex decision making dilemmas in nursing homes regularly involve what I describe as the family, the physician, and the facility triad. Each member of the triad holds stock in the resident’s “best interest” while at the same time courting the “best interests” of a larger domain, i.e. other family relationships and obligations; professional/ethical standards, peer review, and legal concerns; and regulatory compliance and facility management respectively. At some point the behaviors and decisions of each member of the triad affect all others in the triad.

This family’s understanding of the resident’s situation must be further explored. They may be emotionally spent from years of keeping vigil for a person who will never get better and will only continue to get worse. What do they understand about surrogacy and what do they understand constitutes extraordinary versus humane and standard care?

What constitutes a standard of care for physicians in long term care? What is the nature of the patient-family-physician relationship in the face of protracted, irreversible illness? A look at the physician-family relationships here may be helpful in determining the character of the communication between the primary physician and the family. Was there a level of trust established? What is the nature of the divergence of thinking among the doctors in this scenario? Can they reach a consensus on what is medically appropriate and in the best interest of the resident?

The facility is obligated to assure that the resident is protected from harm and that her rights as well as the rights of the facility are respected.

In light of the above, the ethics committee can be viewed in this case first as a protector of the patient assuring that each party’s motives are, in fact, in the patient’s best interests and second as a mediator, facilitating a consensus for what ought to be done.

Who May Speak on Behalf of Mrs. Green—Looking at the Law:
It may benefit the ethics committee to review current state legislation defining terms and specifying legal criteria for the issues at hand. Although the law and ethics are separate disciplines, one concerned with the legal implications of behavior, the other concerned with what ought to be done, it is in the best interest of all concerned to ponder all aspects of the situation.

The state of Maryland recently passed the Health Care Decisions Act (HCDA), House Bill 1243, effective October 1, 1993 and amended previous legislation regarding patient self determination. Sections of the HCDA may be of benefit to the ethics committee in analyzing the situation of Mrs. Green.

The Maryland HCDA addressed the issues of surrogate decision making. The new law states that certain individuals identified in the law “may make decisions about health care for a person who has been certified to be incapable of making an informed decision and who has not appointed a health care agent…”

Mrs. Green did not appoint a health care agent to act on her behalf. In this case, if Mrs. Green had been declared incapacitated as specified in the Maryland law, this family would possess the legal authority to speak on her behalf.

Is Mrs. Green Terminal?
As an ethical matter, it may not be important that Mrs. Green be terminal, if the benefits of her continued treatment pale when compared to the burdens of that treatment and her continued existence. Yet in many jurisdictions, legally falling into the category may be essential. This was the case in Maryland until the Health Care Decisions Act became effective on October 1st. Under the old Maryland law, Mrs. Green would not have been considered terminally ill - her death was not imminent. But under the revised law, family members may also refuse life support on behalf of a patient if the patient has an “end stage” condition. The law defines this as an advanced, progressive, irreversible condition caused by injury, disease or illness: (1) that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and (2) for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective. Mrs. Green’s condition appears to fall within this category.

What Is Considered Aggressive Medical Intervention?
Mrs. Green stated that she didn’t wish extraordinary measures to prolong her life. But what constitutes “extraordinary?” Are simple antibiotics extraordinary? The answer cannot be determined in isolation of an examination of the condition of the patient. As argued by Beauchamp and Childress (1989) what is extraordinary for one patient may not be extraordinary for another. For a patient with the quality of life of Mrs. Green, antibiotics alone might be considered extraordinary.

The Daily Life of Mrs. Green
Who is Mrs. Green? Her family tells us that she would not accept her current state as “consistent with a desirable quality of life”. What was her life like? What does quality of life look like for Mrs. Green? What was her relationship with her family...this family? What are the particulars of this woman’s life that would assist the family, the physicians, and the facility representatives in recommending a plan of care for Mrs. Green?

Perhaps, the real issues that the ethics committee ought to address in this situation lie beyond a discussion of whether to stop or never use antibiotics. Perhaps the ethical consideration in this case would be to explore together a plan of care that attends to the particulars of
who Mrs. Green is, her religion, her beliefs, her social circumstances, and most importantly, her moral values.

CONCLUSION

The issue of antibiotic use in this case if handled only as an isolated topic to be argued out could be relatively simple. But good moral analysis does not tolerate simple answers. Simple answers do not address the entirety of the human situation (Callopy, Boyle, and Jennings, 1991). The real solution reflects on the deeper questions. The answers may be contained in the development of a plan of care that explores all of the questions and looks carefully at the subtleties.

It is the plan of care utilizing the interdisciplinary expertise of the triad of concerned others, i.e., the family, the medical community, and the facility that is of essence here.

Taking the case of Mrs. Green and cases like hers before an ethics committee whose members could generate, direct, and mediate a moral analysis would certainly benefit Mrs. Green. However, the benefits of such analysis in partnership with the family, the physicians, and the facility - the critical triad - could engender the birth of a new nursing home culture and the shedding of an old nursing home paradigm. Such analyses could spur the beginnings of changing cultural expectations of nursing homes.


Submitted by Christa Hojlo, DNSC 
Veterans Affairs Medical Center, 
Washington, D.C.

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**CALENDAR OF EVENTS**

**November**


**November 10th** “The Ethical Implications of Health Care Reform” sponsored by the Law & Health Care Program, University of Maryland School of Law and The Hoffberger Center for Professional Ethics of the University of Baltimore. 5:00 - 6:30 p.m., University of Maryland School of Law. For more information call 410-706-3378.

**November 11th** Baltimore Area Ethics Committee Network Meeting, 4:30 - 6:30 p.m. Manor Care Ruxton, 7001 N. Charles St., Baltimore. Topic: Physician Assisted Suicide. If you are interested in attending please call Fran Stoner at 821-9600.

**November 11th** Wilhelm S. Albrink Memorial Lectureship, James F. Childress, Ph.D., University of Virginia, Dept. of Religious Studies will speak on “The Role of Ethical Principles in Making Health Care Decisions with Patients and Families.” For more information contact the West Virginia Network of Ethics Committees: 800-WVA-MARS.

**November 16th** Metropolitan Washington Bioethics Network, 4:00 - 6:00 p.m. Hospital for Sick Children, Washington, D.C. For more information call 202-682-1581.

**November 29th** “Long Term Care: Can it Be High Caliber and Affordable?” 8:30 a.m. Veteran Affairs Medical Center, Baltimore. Featured Speaker: Senator Barbara Mikulski. For more information call 410-706-8035.

**December**

**December 7th** “The American Way of Health,” 12:00 noon, Westminster Hall, Baltimore, MD. Speaker: Janice Castro, Associate Editor, Time Magazine. For more information call 410-706-8035.

**January**

**January 25th** Metropolitan Washington Bioethics Network, 4:00 - 6:00 p.m. Location and topic TBA.
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