As we begin 1987, the Midwest Bioethics Center has a different look than it did a year ago. We now have a full-time staff of three and one part-time employee. The number of individual and institutional members has grown.

But perhaps the most dramatic change in the past year is the difference we find when talking to others about bioethics. We have noticed that there is a greater awareness of the importance of bioethics issues. Rather than a “What’s that?” response, we more often find that people understand that sophisticated technology brings with it ethical and legal questions. We have been pleased to see the positive response that the Center has received.

The Center has received a grant from the Edward F. Swinney trust, an affiliated trust of The Greater Kansas City Community Foundation. This grant will enable us to coordinate a consortium of hospital and nursing home ethics committees in the greater Kansas City area. We are looking forward to working with the consortium.

In addition, we are sponsoring our first major conference, on “Silver Rights? The Future of Health Care for the Elderly.” This conference will be March 26 and 27, in Kansas City. Information about the conference is in this issue. We hope you will be able to participate with us.

Karen Ritchie M.D., M.A.
President

On September 11, 1986, the Massachusetts Supreme Court took a step toward protecting patients’ rights. (1) The Court ruled that the feeding tube of Paul Brophy, a permanently comatose man who had suffered severe brain damage from a ruptured aneurism could be removed, in accordance with his previously expressed wishes. Brophy, a 49-year-old former Boston firefighter, had been in a coma for 3½ years when the court decision was made. Subsequently, the United States Supreme Court refused to hear his case. Brophy was transferred home, and the feeding tube removed. Eight days later he died.

Paul Brophy had frequently expressed to his family his feelings about accident victims that he had saved, only to see many of them live in a comatose state. Reflecting on these experiences, he had expressed his own wishes: “Don’t ever let me get like that, no way.” Based on evidence that if he were competent to make a decision for himself he would choose to terminate his life, the Court allowed Paul Brophy’s feeding tube to be removed. In other words, the court deemed it to be in the patient’s best interests to discontinue artificial feeding and to be allowed to die.

Brophy’s values and wishes in this matter were reasonably well understood, and the court upheld them. Another person in the same situation with a completely different value system might want artificial feeding continued if they were comatose. The Massachusetts Supreme Court gave support to Paul Brophy’s value system in judging what was “right for the patient.” In doing so, they reaffirmed the common law right of self-determination or autonomy, which allows a person to refuse treatment and to pursue his/her own plan of life despite opposition of others.

The Brophy case is a landmark Massachusetts case in support of self-determination and withholding food and water. However, controversy over these issues remains. Withholding of food and water continues to be a legal question in the Midwest since there is no case law. It becomes an ethical question also when a patient’s wishes are not known. The ethical approach to decision-making has been well described for hopelessly ill and coma- tose patients. (2-7) However, there continues to be a reluctance on the part of families and physicians to withhold food and water from comatose patients (and incompetent, hopelessly ill patients). Some of the beliefs underlying this reluctance are outlined here.

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Churches

Constructive suggestions was encouraging. The mission statement is as follows: "We believe that a key aspect of the growing and maturing Christian life is the development of a meaningful theology, a personalized understanding of how God relates to humankind and works in the world. We believe that this theology should be manifested in a personal system of ethics, a set of principles to guide decisions and actions. We believe that a primary function of the Church is to assist people in developing their own ethical systems. We believe that one way the Church can accomplish this goal is by systematically considering the major social institutions of our society. In this context, we believe that it is appropriate, if not essential, that Saint John's Church consider some of the key issues in contemporary healthcare from a uniquely Christian perspective."

There was an interest from the very beginning in Saint John's hosting a seminar or a series of seminars for the general public. However, it was decided that in order to gain some experience, a series of seminars for our membership would be conducted during our regular church school hours. Three topics were selected, "Living Wills and Organ Transplants," "Paying for Health Care" and "Doctor, Nurse, and Patient Relationship." The first Sunday was devoted to an overview of the general field of bioethics. The panels conducted concurrent sessions on each of the three subjects, repeating the panels for the next two Sundays. This provided our members with the option of participating in two of the three topics. Each panel consisted of three presenters and a moderator, with all except two of the participants being members of our congregation.

The seminars were publicized through the church newsletters and announcements in church services and other meetings. Publicity outside our membership consisted of a news release developed with the assistance of NKHW Marketing Communications. This news release was mailed to both broadcast and print media in the area, and in response I received several calls from hospitals and others concerning dates and topics.

Feedback from those who attended indicated that the sessions were informative and practical. Several of the professional medical people who served on the panels expressed that they felt it was a worthwhile learning experience for them. Overall, the experience was very helpful to the staff and lay leadership of the church, and we plan to offer other topics and other formats in the future.

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Brophy Case

Do otherwise is to violate that basic trust, undermining the relationship.

In some jurisdictions, withholding food and water would be considered a willful act of "killing" (9) and might result in criminal prosecution. The argument here is that withdrawing food and water would cause death that is independent of the underlying illness, whereas the illness can run its own course if food and water are given.

Some feel that withdrawing food and water would cause a painful death, and are concerned about the effect on those around the patient of watching him/her "starve to death." And finally, there is concern that withholding food and water "may bear the seeds of unacceptable social consequences" where "undesirable and unproductive" persons may not receive adequate care. (10)

Arguments for withholding food and water:

Another point of view, however, holds that if the tube does not offer any hope of benefit to the patient it is extraordinary care, and there is no moral obligation to use it. (12) This view stresses that food delivered by tube is similar to air delivered by respirator, since both are mechanical means.

Some are concerned that the dignity of patients is compromised if they have to be sedated or tied down to prevent them from pulling out their tubes (15) and that death can be seen as comfort in some terminal circumstances (17). In those cases, then, continuing artificial feeding may be seen as "cruel" when death is being postponed. In this view, "at the end of a long downhill course, not eating is a natural letting go of life." (15)

There has been considerable discussion about the question of suffering while not being fed. Some feel that thirst and dry mouth are the only serious and common symptoms caused by dehydration in terminally ill patients and may be relieved by maintaining moisture in the mouth or by small amounts of oral fluids. (16)

Others add that hand-feedings, even if they provide inadequate nutrition may

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Arguments for providing food and water:

First is the belief that food and water are not medical treatment, but routine comfort care that "preserves the life of the embodied human being" (9) and that maintaining the dignity of the patient requires giving food and water even when other care is withdrawn. Some point out that the expectation of receiving food and water is essential in maintaining trust in a physician-patient relationship, and to

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meet more of the patient's (psychosocial) needs than tube feedings that deliver adequate calories impersonally. (15) Also, "if patients are offered food and fluid by hand, and consistently refuse them, it seems unlikely that they are experiencing hunger and thirst." (15)

When the patient's wishes are known, there should be less reluctance to withhold food and water. The patient's right to self-determination has been consistently supported by the courts throughout the country. (8, 18-20) The Brophy case adds strength to this position since it involved a comatose person who was not terminally ill but whose wishes were known.

As a result of the Brophy case, it may be easier for health care personnel to discuss treatment decisions with families of incompetent patients, whether chronically comatose with a life expectancy of years (persistent vegetative state) or terminally ill with a life expectancy of weeks. The case relieves some of the insecurity in decision-making for these patients. When the patient's wishes are known, much of the burden of decision-making is removed from the family, who will then not have to bear the guilt of "pulling the plug" or "pulling the tube". They will know that the course is what the patient would have chosen. Also, the patient's wishes may bring unity to what could have been differing opinions between family members and health care providers regarding "what is right for the patient." Decision making is easier when the patient's wishes are explicit.

Cases like Brophy encourage competent people to make explicit their wishes about future health care decisions in the event they become incompetent and can no longer decide for themselves. (21) Living wills can be of help, especially if specific instructions are added. The living wills of several states, including Missouri, do not allow their use to withhold food and water from a terminally ill person. In those states, a person who would prefer to not receive food and water when terminally ill would have to add additional instructions to the document or on a separate sheet of paper. These additional instructions would be legally controversial if the case went to court in states which have no case law regarding this issue. However, courts have generally supported the patient's wishes, following the principle of the right to self-determination.

Thus, the Brophy case has sent a message that if you discuss your values regarding future health care decisions with your family and physician and document your wishes in writing, there is a reasonable chance the courts will support your choices in the event that you become incompetent. With more courts continuing to support this view, decision-making will stay more securely within the family of the incompetent patient, the physician, and the health care team, without fear of the case going to court.

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Bibliography

AMA, much hinges on Ludmerer’s meaning of “participated in the creation.” Creation, to forge events in any lasting manner, must go beyond mere conception. Implementation, too is involved. We did not create an automotive society merely by solving the conceptual problems of the internal combustion engine. Henry Ford’s assembly line was required as well. Similarly, one does not create modern medical education solely by conceiving its ideal form. Ideas must be widely in place and working successfully before creation is complete. The efforts of both Flexner and the AMA were instrumental in accelerating the reforms that Ludmerer and others have shown were already underway in scattered medical schools. To that extent surely it is more than semantics to contend that Flexner and the AMA “participated” in the “creation” of modern medical education. In addition, Flexner

raised more money than any other person to assist selected schools in their efforts at reform. These efforts gave fortunate faculties the opportunity to put pre-existing ideas to work on a wide scale long before this would have been possible otherwise. For me, this too was a part of the creation.

Few authors can hope to produce a major work without a few errors creeping in. Ludmerer credits Oliver Wendell Holmes with discovering the mode of transmission of puerperal fever (p.26), but all of the deductions he reached had been arrived at by the same investigative approach as far back as 1795 by Alexander Gordon, (which, incidentally, Holmes acknowledged.) Pasteur is held to have disproved spontaneous generation (p.76). In truth he never constructed an experiment that disproved spontaneous generation, a logical impossibility given the tools at his disposal at the time.

But these are minor lapses which do not weaken the essential conclusion that Ludmerer’s Learning to Heal is the most incisive and richly documented analysis of American medical education yet to appear on the subject. It is a genuinely important book.

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Catastrophic Health

daily copayments for lengthy stays would be eliminated and the $520 deductible could be applied no more than twice a year.

The new cost-sharing cap would be financed through a premium that would rise each year so that it always covers the entire cost of the new cost-sharing cap. Currently, this would require a $4.92 increase in the $15.50 monthly premium the program’s 32 million beneficiaries now pay for supplemental medical insurance.

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Correction

Some references in the article “The Brophy Case: Courts Support Self-Determination” in our last issue, 3:1, Winter 1987 were inadvertently omitted. The following is a complete list of references.

Bibliography

18. Paris, J.J. and Reardon, F.E. Court responses to withholding or withdrawing artificial nutrition and fluids. JAMA, 1985; 253: 2243-2245.