

CARE OF THE DYING: A CATHOLIC PERSPECTIVE

Part II: Social and Political Context—Catholic Providers Must Exemplify a Caring Community

Because of the growing movement toward assisted suicide and euthanasia, in 1990 the Catholic Health Association (CHA) convened a group of its members to clarify and extend the insights of Catholic theological teaching to address issues at the end of life. From this effort came the foundational document, *Care of the Dying: A Catholic Perspective* (CHA, St. Louis, 1993).

In this issue, *Health Progress* presents an excerpt of the second part of that document, "Social and Political Context." In March we published the first part, "Cultural Context." Excerpts of the other two parts will appear in subsequent issues: "Clinical Context" in May; and "Theological, Moral, and Pastoral Response" in June.

The complete text of *Care of the Dying: A Catholic Perspective* has been sent to all CHA members. Additional copies are available from CHA, 4455 Woodson Road, St. Louis, MO 63134-3797, 314-253-3458. The cost for one to

four copies is \$9 each; five to nine copies, \$7.50 each; and ten or more copies, \$6 each.

The increased level of activity in state legislatures and courts regarding "natural death" and the "right to die" demands that Catholic health-care providers address the social and political dimensions of issues about the end of life. A developing "war of words" threatens to refashion our understanding of death, dying, and refusal of treatment. Clear and consistent definitions of major terms are therefore important.

The first part of this article clarifies the value-laden words most frequently used in the media and in public debates on issues about the end of life. The second part discusses how these issues are being handled in the legislative arena, the media, the courts, and healthcare institutions.

Summary Fears of abandonment and isolation in an institution have increased the public demand for euthanasia and assisted suicide. To quell this movement, Catholic healthcare providers must provide a caring community where patients and care givers enable each other to confront the fear of death and find support in living with human limitation.

To begin to address the social and political dimensions of issues about the end of life, Catholic healthcare providers must use clear and consistent definitions of the terms used to describe these issues, such as death with dignity, right to die, euthanasia, allowing to die, and assisted suicide.

By acknowledging the influence of the media in forming attitudes and opinions, healthcare institutions can seize opportunities for public education on fundamental human and religious values. The

first effort has to be directed toward educating members of the media.

The Catholic Church supports the concept of advance directives, which provide an opportunity for people to express their values and the ways they would expect those values to be honored in decisions about medical treatment.

Courts' role in resolving decisions about treatment should be limited. Patient self-determination is best exercised when a patient (or surrogate), in consultation with a physician, decides what is best.

Catholic healthcare institutions should advocate for legislation that fosters an appropriate balance between protecting a patient's right to self-determination and the state's interests to protect life. At the same time, institutions' advocacy efforts should demand sufficient resources for holistic care for the dying.

TERMINOLOGY

Words mean different things to different people. Therefore clarifying the terms used in public debate is necessary to avoid fundamental misunderstandings and speak a common language about how best to care for patients at the end of life.

Death Most state laws defining death now reflect the requirements listed in the Uniform Determination of Death Act:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

In recent years, proposals to revise the brain criteria for determining death have been debated vigorously. The proposed revision, called "cerebral" or "neocortical" death, would determine death on the basis of "the irreversible cessation of those brain functions necessary to sustain any level of consciousness."

However, "neocortical" death is not to be confused with brain death, which is defined as the total cessation of all functions of the entire brain. In the Karen Quinlan case, for example, the U.S. Supreme Court ruled that the patient was "cerebrally dead" but not brain dead.¹ While the debate continues, the only acceptable criteria for determining death are those for *whole brain* death.

Death with Dignity "Death with dignity" means dying in a way that is not unduly burdened by the prolonged use of life-sustaining technology in an alienating and depersonalizing environment. From a Catholic perspective, the dignity of the person derives from his or her relationship with God. Death is a passage every person inevitably must face to enter the fullness of this relationship.

Everyone has the obligation to ease the passage and to accompany the dying person until the end, but there is no obligation to use every available means to prolong life in every situation.

Right to Die Often when this phrase is used, the "right" at stake is not to die, but to request euthanasia or assisted suicide.

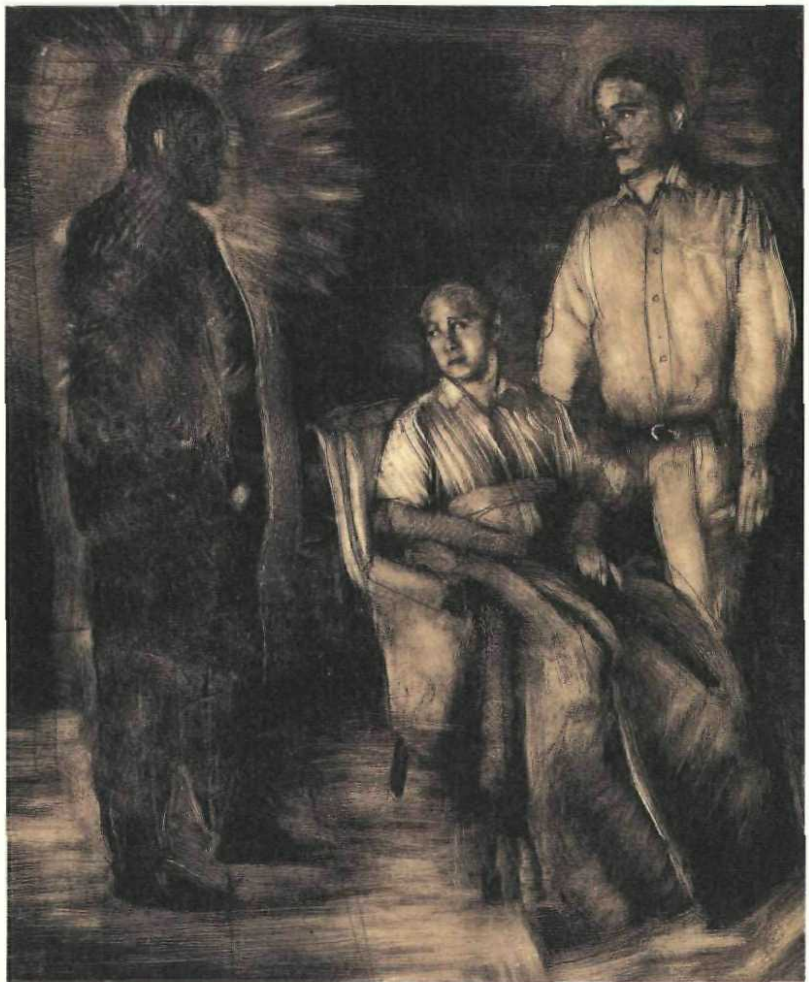
American law does not recognize a constitutionally protected right to die. In the *Cruzan* case, the U.S. Supreme Court did recognize an individual's "liberty interest" in refusing unwanted medical treatment.² According to the Court, this interest can be limited by procedural safeguards designed to protect the state's interest in preserving life and to ensure that others act in conformity with the patient's wishes.

The Catholic Church opposes an absolute "right to die." Catholic tradition values persons' self-determination in making medical decisions, including the refusal of life-sustaining measures, as one of the most basic expressions of their dignity. However, Catholic moral tradition limits this right to refuse treatment on the basis of a moral order that requires human beings to act as responsible stewards of their lives and health, not as absolute arbiters of their ultimate destiny. Catholic teaching advocates less emphasis on individual autonomy and freedom of choice, which are so prized in the American ethos.

Euthanasia According to official Catholic teaching, euthanasia is "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated."³

Euthanasia is *active* and *voluntary* when a person explicitly requests help to die and a care giver then gives a lethal injection, for example. Euthanasia is *active* and *involuntary* when directed toward a person who is incapable of making a request to die (such as an infant, a young child, a

To combat the growing support for euthanasia, Catholic healthcare providers must become ideal examples of a caring community.



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mentally retarded person, or a comatose patient) but whose proxy (such as a parent, spouse, guardian, or physician) makes the request and makes certain that the lethal procedure is carried out. Neither of these forms of active euthanasia is morally acceptable.

Killing or Allowing to Die The Catholic medicomoral tradition maintains a moral difference between these actions. "Killing" refers to a human agent being morally responsible for causing death. A physician "kills" the patient if, for example, the physician intervenes with a lethal injection, or withholds or withdraws treatment that *should be* provided because it is *reasonable* to do so.

"Allowing to die" refers to stopping treatment that is burdensome or offers no reasonable hope of benefit so that the underlying pathological condition, which called for the use of the treatment in the first place, will run its course and eventually cause the patient's death. In such an instance, no one is morally responsible for the death, since the fatal pathological condition caused it.

The distinction between killing and allowing to die is best retained in euthanasia debates because it helps differentiate between deaths for which we are morally responsible and those for which we are not.

Mercy Killing "Mercy killing" is another name for euthanasia. It is used to emphasize that persons who request euthanasia do so to escape the physical and mental suffering that may accompany the terminal stages of a fatal disease. Also, it suggests that persons who commit euthanasia do so out of compassion.

According to the *Vatican Declaration on Euthanasia*, "mercy killing" is killing "for the purpose of putting an end to extreme suffering, or saving abnormal babies, the mentally ill, or the incurably sick from the prolongation, perhaps for many years, of a miserable life, which could impose too heavy a burden on their families and society."⁴

Suicide Suicide is the intentional and deliberate taking of one's own life. Most state laws have decriminalized suicide, but public safety officials in every municipality intervene as a matter of course to prevent individuals from committing suicide.

The Catholic moral tradition rejects suicide as a way to escape prolonged and barely tolerable pain. The Church, however, refrains from passing judgment on someone who resorts to suicide in desperation.

Assisted Suicide (Aid in Dying) Although suicide has been decriminalized, in most states helping someone commit suicide is treated as criminal homicide. "Homicide" is defined by *Black's Law Dictionary* as "the killing of one human being by

the act, procurement, or omission of another."⁵ It is a crime only if done with criminal intent.

The term "aid in dying" conceals more than it reveals. All sorts of aid can be given to the dying, such as companionship, love, and appropriate pain management. However, the term is not being used with these definitions in mind. Recently used in efforts to legalize assisted suicide, "aid in dying" refers to physicians taking steps to help terminally ill patients commit suicide by providing the means and the knowledge of how to take one's own life. The Michigan cases involving Jack Kevorkian, MD, who helped patients self-administer a lethal dose of drugs, are notorious examples of assisted suicide, or aid in dying.

The *Vatican Declaration on Euthanasia* is clear in its moral evaluation of assisted suicide:

No one is permitted to ask for this act of killing, either for self or for another person entrusted to his or her care, nor can one consent to it, either explicitly or implicitly. Nor can any authority legitimately recommend or permit such an action. For it is a question of the violation of the divine law, an offense against the dignity of the human person, a crime against life, and an attack on humanity.⁶

Persistent Vegetative State A persistent vegetative state (PVS) occurs with the functional loss of the cerebral hemispheres of the brain, which control consciousness, awareness, and other voluntary and involuntary actions. However, in PVS the functions controlled by the brain stem continue, such as respiration, pupillary response to light, and the cough and gag reflexes. Patients in a PVS may exhibit many normal brain-stem functions; however, they are completely unconscious and unaware of their environment and exhibit no voluntary reactions or responses.

In contrast, *coma* is a state of unconsciousness in which a person does not have sleep-wake cycles and exhibits no voluntary reactions or responses. The person in a coma appears to be asleep.

A few dramatic cases of patients "waking up" after a long period of what was believed to be permanent unconsciousness have been widely and somewhat sensationally reported in the media, suggesting to some that life support should never be withheld. Physicians, however, have questioned whether these few patients were accurately diagnosed from the beginning.

PUBLIC OPINION AND THE MEDIA

Opinion Polls Opinion polls over the past two decades have shown a steady increase in popular

support for euthanasia and assisted suicide. In May 1990 the Washington, DC-based Times Mirror Center for People and the Press conducted a national telephone survey on issues surrounding the end of life. It compared the results with those of similar surveys done over the past 20 years. The analysis showed an increase in public support for the patient's right to choose and for the use of proxies as decision makers. The results also noted a trend toward greater acceptance of suicide in the face of a terminal disease.

Such surveys both reflect and create societal attitudes and values about issues pertaining to the end of life and care of the dying. The statistics should be examined with caution. Although national opinion polls sometimes create the impression of homogeneity in attitudes and opinions, real differences do exist but fail to show up because of how questions are asked or how data are analyzed.

Another factor to consider is the impact of influential regional public attitudes. For example, since major news networks are headquartered in the Northeast, this area influences to a great extent the public information broadcast about events such as Kevorkian's "death machine." Also, the entertainment industry, primarily based in southern California, shapes public attitudes on these questions through television and films.

Mass Media Increasingly, medical and ethical issues surrounding the end of life are appearing in news stories, in popular magazines, in best-selling books, and on national television. Even more common are television dramas that depict anguishing decisions about forgoing and discontinuing medical treatment and about taking one's own life.

Derek Humphry's how-to book on effective suicide, *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying*, fills people's consciousness with a new meaning for a "good death" (the translation of the Greek "euthanasia"). The book's popularity is a strong indictment of healthcare systems that fail to control pain and fail to provide emotional, social, and spiritual support.

By acknowledging the influence of the media in forming attitudes and opinions, healthcare institutions can seize opportunities for public education on fundamental human and religious values. The first effort has to be directed toward educating the members of the media themselves. Some strategies for informing the media are to:

- Host regular informational meetings for media leaders
- Offer to serve as an information resource
- Host public debates on important and controversial end-of-life issues

IMPLICATIONS FOR CATHOLIC HEALTHCARE

Social and political forces influence how Americans view the dying process. To position the Catholic healing tradition as an important voice in the debate on end-of-life issues, Catholic healthcare organizations must be certain the public hears the Church's word.

- Because the major terms used in the public debate have various definitions, Catholic healthcare providers must be careful to avoid using slogans and to be clear about the meaning of key terms that express important values.

- Public opinion is strongly influenced by the media and by the way questions are asked in polls. We must educate members of the media about end-of-life issues covered in news stories, television dramas, popular magazine articles, and how-to suicide manuals.

- As federal and state legislation mandating advance directives has expanded, Catholic healthcare providers must educate the community on advance directives and educate caregivers on respecting the preferences expressed in these documents.

- The courts have frequently become involved in decisions that should have been made by the patient or proxy after dialogue with the physician. To avoid unnecessary recourse to the courts, we must provide effective means within the healthcare institution to support the primary decision makers and to mediate conflicts.

- Since most deaths occur in healthcare institutions, Catholic healthcare providers must (1) transform current policy and practice into ways of making decisions about treatment that are more respectful of human dignity, (2) provide trained staff who can help patients and families act responsibly, and (3) advocate legislative structures that foster a balance between protecting patients' self-interest and the common good.

- Meet with medical reporters to discuss issues such as those covered here

LEGISLATIVE FRAMEWORK

Advance Directives Legislative debates over the past five to ten years have centered on ways to enable individuals to exercise their right to refuse treatment without compromising the interests of the state in protecting life.

In the wake of California's Natural Death Act (passed in 1976), most states have enacted legislation regarding both the living will and the durable power of attorney for healthcare. Current debates focus on such issues as educating patients on their right to refuse treatment, determining the role of the surrogate decision maker, and allowing the withdrawal of medically assisted nutrition and hydration. Other debates, as seen in legislative initiatives on the West Coast, center on the legalization of physician-assisted suicide.

The common-law tradition of informed consent is the basis for more recent legislation protecting a patient's right to refuse unwanted treatments. In virtually every state the existence of refusal-of-treatment legislation, such as laws

regarding the living will and durable power of attorney for healthcare, suggests that many people believe they have lost control over decision making about medical treatment for themselves or their loved ones. The enactment of these laws also suggests that physicians feel they may need protection when acting on patients' request to limit or stop treatment.

Most of the legislative activity has been at the state level. However, the Patient Self-Determination Act, which became federal law December 1, 1991, requires all healthcare facilities receiving Medicare funds to:

- Provide patients with information about their rights to accept or refuse treatment and to make an advance directive
- Maintain written policies and procedures to ensure that patients receive such information in written form
- Document on the patient's medical record whether the patient has executed an advance directive
- Educate both staff and the community about advance directives

There is no fail-safe method to ensure that one's wishes regarding treatment will be honored should one become incompetent. The advantage of advance directives is that they are usually valuable indicators of a person's preferences. Their greatest benefit, however, is to provide an opportunity for people to express their values and the ways they would expect those values to be honored in decisions about their medical treatment and to discuss these details with family members, close friends, and physicians.

The Catholic Church supports the concept of an advance directive; however, it would oppose the request for euthanasia or assisted suicide, as well as the request to do everything regardless of cost in order to keep a physical organism alive. Neither extreme is acceptable.

In the context of so much high-technology medicine, Catholics should be encouraged to establish advance directives, since they may be the most effective way to exercise stewardship over one's life and health. Catholic healthcare providers should regard these documents as instruments to help them communicate more effective-

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ly with patients about their wishes. The process through which an advance directive is developed and discussed with physician, family, and close friends can be one of the most meaningful ways to stimulate reflection on the values of the Catholic tradition.

Proxy Decisions The role of the proxy or surrogate decision maker is to represent the expressed wishes or, when those are not

known, the best interests of the patient for whom he or she speaks. Some states limit the scope of the surrogate's authority to make certain decisions, such as prohibiting a surrogate from withdrawing medically provided fluids and nutrition. Typically a surrogate designated by the patient in a durable power of attorney document, for example, has greater authority than family members who are not so formally designated. But without such formal designation, healthcare institutions and legal organizations tend to defer to close family members to communicate the wishes of an incompetent or incapacitated patient.

Goals of Legislation The ideal legislative framework balances the rights of the patient (and those of his or her surrogate), the conscience of healthcare providers, and the interests of the state. The fundamental right in need of protection is the patients' self-determination or autonomy. But patients also need to be protected from neglect or abuse by healthcare providers and others who may withhold beneficial treatment. The state is empowered to act on their behalf. The interests of the state traditionally are (1) protecting life, (2) preventing suicide, (3) protecting the interests of innocent third parties, and (4) safeguarding the integrity of the medical profession.

Two statements published by the Committee for Pro-Life Activities of the National Conference of Catholic Bishops (NCCB) in 1985 and 1986⁸ expressed concern that legislation reflect:

- An emphasis on the societal interest in preserving life, preventing suicide and homicide, and protecting the integrity of the medical profession
- Some limits to the immunities given providers who withdraw life-sustaining treatment
- A presumption in favor of continuing nutrition and hydration to sustain life, while recognizing exceptional circumstances⁹

- Provisions that encourage communication among patient, family, and physician
- Protection for the unborn child of a terminally ill mother

The 1986 document also urged that there be an open public debate before decisions are made to limit the amount of funds available in certain healthcare settings.

Legislative support for patient self-determination can be a positive step toward encouraging patients to participate in decisions about their medical treatment. Decriminalizing physician-assisted suicide, however, could lead to serious abuses because of the social and cultural inequities that exist in U.S. healthcare. For example, dying patients could choose active interventions to end their lives because of a lack of financial or emotional support in dying. In addition, vulnerable and incompetent patients might be assisted in terminating life as a solution to the economic and other burdens of caring for a growing elderly and chronically ill population. Finally, our judicial system could mandate that physicians advise patients of a constitutional right to physician-assisted suicide, thus influencing patients' choices because of physician pressure, even if unconscious and unintended.

ROLE OF THE COURTS

The courts provide a forum for adjudicating conflicts between the rights of individuals and state interests, as well as those conflicts arising between parties over their respective rights and liabilities. The patient's right to consent to or refuse treatment is the background for judicial deliberation.

Some cases regarding the right to refuse treatment have been decided on the basis of a state or federal "right to privacy." Other courts, disputing the existence of this constitutional right to privacy, have nevertheless ruled on behalf of an individual's right to refuse treatment on the basis of a "liberty interest." In several cases,¹⁰ the state court ruled in favor of the state's interest in preserving life, requiring "clear and convincing" evidence (as in a written advance directive) from the patient before permitting the withholding or withdrawal of life-sustaining treatment.

The degree to which a court should be active in resolving decisions about treatment is an issue of great importance. Put simply, the issue is whether treatment decisions should be made by a court rather than the patient (or by his or her surrogate). Patient self-determination is properly exercised when a patient (or surrogate), in consultation with a physician, decides what is best. Programs provided by healthcare ethics committees or pastoral care staffs can also help support

the primary decision maker and, if necessary, mediate conflicts.

Another concern about the role of the courts is their relationship to the legislature. Ideally, a court renders judgment within a legal framework that gives sufficient weight to the public interest. However, state laws reflect not only the public mores in a particular state or region, but considerable political maneuvering by special interest groups as well. What is truly in the public interest is most likely to be achieved if public debate is informed, vigorous, and widely participative.

ROLE OF HEALTHCARE INSTITUTIONS

Healthcare institutions have an indispensable role in facilitating private and public moral discussion on questions of refusing treatment. Since most deaths occur in these institutions, they are the places where most of the decisions in question are made. Although healthcare institutions strive to be caring communities, people are often alienated by institutional policies and physician and nurse practice patterns. This environment fosters the imperative to treat at all costs; it may inadvertently create public sympathy with sentiments such as "right to die" and "death with dignity."

Healthcare institutions have significant opportunities to assume a leadership role in transforming current policy and practice into ways of making decisions about treatment that are more humane and dignified. For example, institutional administrators need to recognize the limitation of resources. To effectively support patients' right and responsibility to guide the course of their own treatment, administrators must make sure their staff understands the issues and can help patients and families act responsibly and come to terms with the limits imposed by sickness and ultimately death.

Even in a supportive environment, however, some patients may request actions that are inconsistent with the policies of a healthcare institution. In such cases, the institution must carefully balance its right to act in accord with its mission and expressed values with the right of the individual to have his or her wishes honored. A patient's right to refuse treatment is not absolute. However, the institution has a duty to show good reason for not honoring a patient's wishes. This is especially important when the institution has no explicit public policy that would alert patients to an institutionally imposed limitation on their right to refuse treatment.

Finally, healthcare institutions can play an important role independently or through national and state associations by advocating legislation that fosters an appropriate balance between pro-

Continued on page 41

CARE OF THE DYING

Continued from page 21

protecting a patient's right to self-determination and the state's interests to protect life. At the same time, their advocacy efforts should demand sufficient resources for holistic care for the dying.

CARING COMMUNITY

The public's demands for euthanasia and assisted suicide are in part an expression of people's fears of abandonment and isolation in an institution. Catholic healthcare providers must become ideal examples of a caring community, where patients and care givers enable each other to confront the fear of death and find support in living with human limitation. □

NOTES

1. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).
2. *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 1990.
3. Congregation for the Doctrine of the Faith, "Declaration on Euthanasia," *Origins*, vol. 10, 1980, pp. 154-157.
4. Congregation for the Doctrine of the Faith.
5. Henry Campbell Black, *Black's Law Dictionary*, 6th ed., West Publishing, St. Paul, MN, 1990, p. 734.
6. Congregation for the Doctrine of the Faith.
7. Derek Humphry, *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying*, Hemlock Society, Eugene, OR, 1991.
8. Committee for Pro-Life Activities, National Conference of Catholic Bishops, "Guidelines for Legislation of Life-Sustaining Treatment," *Origins*, January 24, 1985, pp. 526-528; Committee for Pro-Life Activities, National Conference of Catholic Bishops, A Commentary on the Uniform Rights of the Terminally Ill Act, U.S. Catholic Conference, Washington, DC, June 1986.
9. See also Committee for Pro-Life Activities, National Conference of Catholic Bishops, "Nutrition and Hydration: Moral and Pastoral Reflections," *Origins*, April 9, 1992, pp. 705-712.
10. *Cruzan: In the Matter of Westchester County Medical Center, on Behalf of Mary O'Connor*, 534 NYS 2d, 1988.

SPONSORSHIP NETWORKS

Continued from page 37

Despite good-faith efforts during consensus building, collaboration is susceptible to collapse if implementation issues are not anticipated and addressed. I cannot overemphasize the importance of process in planning and conducting successful collaborations.

Assessing The final stage consists of monitoring programs to ensure they are achieving the intended goals. This may lead to adjusting either the goals or the method of implementation. This ongoing evaluation also leads to additional problem setting, thus beginning the cycle again.

A COUNTERCULTURAL VISION

Sponsorship has two dimensions: the canonical stewardship that focus-

es on control of sponsored entities, and an influence on the entities' philosophy, mission, vision, and values. As radical changes occur in healthcare delivery—and the hospital ceases to be the center of healthcare delivery—the issue of control as it relates to property will become less relevant.

Thus sponsors are challenged to seek new ways to influence the philosophy, mission, visions, and values exemplified by their sponsored entities. Sponsorship networks offer a way to do that and provide a structure for the future that eventually could be the vehicle for Catholic sponsors and providers in a region to carry on the Church's healing ministry. □

JUNE 17 - 19, 1993

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TRUSTEES: STEWARDS OF MISSION CATHOLIC SPONSORSHIP IN A PLURALISTIC SOCIETY

This institute seeks to improve the ability of health care leaders to promote the Catholic identity of Catholic health care facilities. Upon completion of the institute, participants will be able to:

- Articulate the relationship between Catholic-sponsored health facilities and the mission of the Church
- Define their responsibilities as stewards of the ministry of Catholic health care
- Plan the future of their health care facility in light of the mission of the Church
- Address ethical issues confronting the ministry of Catholic health care in the '90s

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