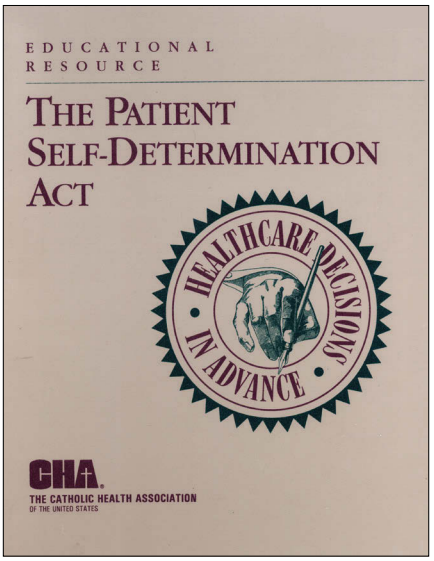
CHA
Catholic Health Association of the United States

CELEBRATING 100 YEARS

BIOETHICS
Questions & Controversies

By PAMELA SCHAEFFER, PhD

The 1990s brought many new ethical questions and controversies to health care in the U.S. and important shifts in the delivery of care in cases of serious illness and end of life. For Catholic health care, the growth of large systems, integrated delivery networks and managed care often demanded collaborative ventures between Catholic and other-than-Catholic organizations and called for unprecedented theological analysis of morally permissible or impermissible relationships.



New medical technologies and pharmacological advances had a distinctly positive side — they allowed patients who previously would have died at early stages of illness to lead longer, more productive lives. But some innovations, particularly those related to reproductive issues or end-of-life care, were fraught with moral implications for Catholic health care.

Further, a series of court cases brought by families seeking to remove life-sustaining measures from patients in persistent vegetative states resulted in new federal legislation requiring hospitals and long-term care facilities to make efforts to determine patients' wishes while they could still speak for themselves.

THE PATIENT SELF-DETERMINATION ACT

The new federal law, the Patient Self-Determination Act of 1991, brought significant changes to hospital-patient relations in all U.S. hospitals. The two most prominent court cases precipitating the new law were brought by the parents of Karen Ann Quinlan and the parents of Nancy Beth Cruzan. Both patients were young women lingering in persistent vegetative states, that is, unconscious with no reasonable hope for recovery, and both sets of parents were blocked in seeking to have life-sustaining

interventions withdrawn. In the Quinlan case, the intervention was a ventilator; in the Cruzan case, it was medically administered nutrition and hydration. Both sets of parents ultimately sued and eventually won, but the court battles were long and arduous.

The two combined cases, among others, aroused widespread concerns among people who worried that they or family members might someday be in a similar situation and be kept alive with unwanted medical interventions.

The cases not only raised controversial questions in Catholic bioethics, they were a major factor in the movement to legalize physician-assisted suicide and euthanasia on the one side, and an impetus in the evolution of palliative comfort care to reduce suffering in the seriously ill on the other.

The Cruzan case in particular was directly linked to the Patient Self-Determination Act because it led to a landmark ruling in the U.S. Supreme Court that effectively established a constitutional right for persons to make their own medical decisions and, in advance of becoming incapacitated, to communicate a desire to forgo treatments intended to forestall death.

Trudy Sasseen was among the CHA staff that compiled more than 3,000 binders on the Patient Self-Determination Act.

In its ruling, the Supreme Court upheld the Missouri Supreme Court's 1990 decision, which declared that, absent clear and convincing evidence of Nancy Cruzan's wishes to the contrary, the state could legally prohibit removal of her feeding tube.

In effect the Supreme Court ruling acknowledged that a patient's wishes regarding end-of-life care could legally be honored, even were she or he unable to communicate them, so long as credible evidence of what those wishes could be shown.

Under the terms of the Patient Self-Determination Act, health care organizations receiving Medicare or Medicaid were now required to ask patients for advance directives for health care or to invite and help patients prepare them. Facilities also were required to inform patients of any policies that might interfere with their ability to honor advance directives. In the case of Catholic hospitals, that would include actions prohibited by the *Ethical and Religious Directives for Catholic Health Care Services*.

In March 1991, CHA launched multi-pronged educational efforts for members in advance of the December rollout of the law. These were aimed in part at clarifying church teaching on life-sustaining measures and helping members communicate their policies. They also were meant to assure the public that advance directives for end-of-life care would be honored in Catholic facilities, short of allowing euthanasia or physician-assisted suicide.

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1991

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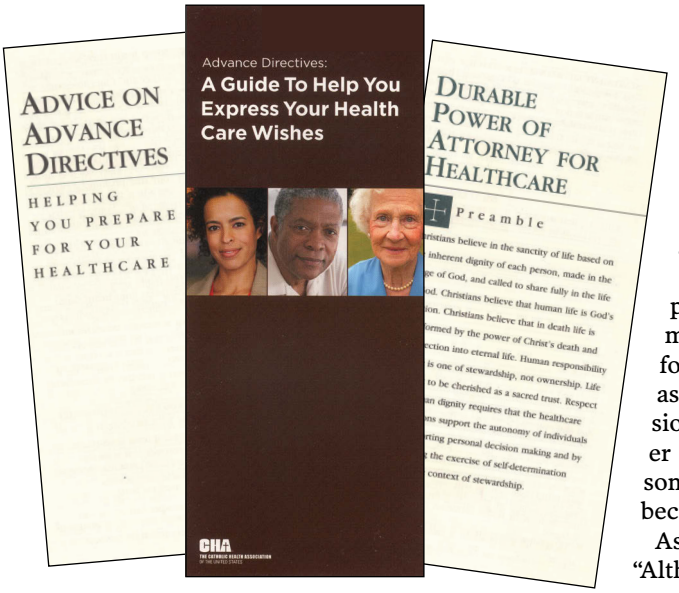


tions at the Catholic Health Assembly that year, along with a series of regional meetings convened by CHA and known as Project 1991, intended to help members understand requirements of the legislation and its ethical and legal dimensions.

A major, ongoing component of the campaign was to provide CHA members with models of effective and understandable forms for providing advance directives or assigning responsibility for health care decisions to another party through a durable power of attorney for health care, should a person's decision-making or expressive capacities become compromised.

As CHA noted in a brochure for Project 1991, "Although many issues remain unresolved, the responsibility of health care professionals is clear: to provide leadership, guidance and support for all who are involved in making critical end-of-life decisions."

1994

CHA announced the bishops' approval of the revised Ethical and Religious Directives for Catholic Health Care Services *in the Dec. 1, 1994, issue of* Catholic Health World.

ETHICAL AND RELIGIOUS DIRECTIVES REVISED

The unresolved issues, which included both end-of-life care and moral dilemmas arising from the growing numbers of collaborative arrangements between Catholic and other-than-Catholic organizations, prompted U.S. bishops to undertake in the late 1980s the first major revision of the *Ethical and Religious Directives for Catholic Health Care Services* since 1971. There was a need to address new questions for ministry leaders and health care professionals and for reinterpreting some of the older directives in light of medical innovations. Additionally, medical issues creating legitimate differences of opinion among bishops and Catholic moral theologians called for discussion and clarification.

The revision, the result of a seven-year deliberative process, was completed and approved by the National Conference of Catholic Bishops in 1994, following Vatican review. It was based on consultations with CHA and four other organizations specializing in moral theology and bioethics, whose input was solicited by a subcommittee of the Committee on Doctrine at the National Conference of Catholic Bishops. The other consultants were the Pope John XXIII Center, the Center of Health Care Ethics/Saint Louis University Health Sciences, the Medical-Moral Board of the Archdiocese of San Francisco and the Kennedy Institute of Ethics at Georgetown University.

Over the seven years, CHA supplied the bishops with hundreds of pages of reports and analysis as well as critiques of successive drafts. These were based on meetings and correspondence involving some 300 theologians, ethicists, physicians, nurses, chaplains, social workers, hospital sponsors and

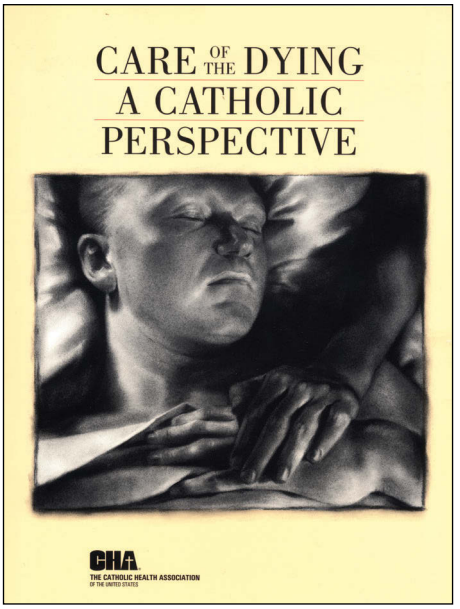
administrators and others. CHA was among the consulting groups that saw a need to set the directives within a positive context of the church's historic healing mission and its social justice mission, and to convey the pastoral concern of Catholic health care for the whole human person, not just the diseased body. Further, new reproductive technologies, such as *in vitro* fertilization, needed to be addressed.

CHA announced the bishops' approval of the revised *Ethical and Religious Directives for Catholic Health Care Services* in the Dec. 1, 1994, issue of *Catholic Health World*. Following their publication in 1995, a series of articles was published in *Health Progress*, beginning with the April issue. Authors of the series were two experts known to the Catholic health ministry: Sr. Jean deBlois, CSJ, PhD, CHA's senior associate for ethics, and Fr. Kevin O'Rourke, OP, JDC, director of the Center for Health Care Ethics at Saint Louis University's Health Sciences Center.

According to Sr. deBlois and Fr. O'Rourke, the revision met the need for guidance on new ecclesial and social realities and medical innovations. Rather than the straightforward list of directives, as in the 1971 edition, the revised document was divided into six sections, each with an introductory essay on the scriptural, theological and social dimensions of the section's theme, followed by specific directives. The sections focused on the social responsibility of Catholic health care, the pastoral and spiritual responsibility, the professional-patient relationship, issues in care for the beginning of life, issues in care for the dying, and forming new partnerships with health care organizations and providers.

Sr. Jean deBlois, CSJ, PhD

Fr. Kevin O'Rourke, OP, JDC



1998

By 1998, there were 13 Catholic health care systems with facilities in 49 states that had joined the Supportive Care Coalition.

IMPROVING END-OF-LIFE CARE

New medical technologies and treatments able to prolong life for patients with terminal illnesses and the elderly, combined with a tendency in American health care to aggressively fend off death, put greater public focus on negative experiences of patients who often experienced poor management of their pain. Complaints emerged, too, over neglect of the psychological, social and spiritual needs of patients and their families as they often suffered severe emotional and financial burdens. Public acceptance of physician-assisted suicide and euthanasia was growing, and some organizations portrayed the Catholic Church in their campaigns as uncaring about the suffering of patients. These organizations included the pro-euthanasia group known as the Hemlock Society, whose successor groups include Compassion in Dying Federation and, most recently, Compassion & Choices.

CHA responded in 1993, with the work of a task force culminating in publication of a comprehensive resource for members, "Care of the Dying: A Catholic Perspective." The 69-page booklet described the cultural, social-political and clinical contexts that underscored the need for such a resource, and a final section titled "Theological, Pastoral and Moral Response." The booklet was incorporated into an educational manual of more than 200 pages, consisting of lesson plans, case histories and other materials for four audiences: trustees and sponsors, administrators, physicians and nurses, and mission leaders.

In 1992 and 1994, several Catholic health care systems in the Pacific Northwest, with financial support from CHA, vigorously opposed euthanasia and assisted suicide referenda in Washington and Oregon. Following the 1994 passage of the Oregon Death with Dignity Act, these systems committed to comprehensive research to understand and better meet the needs of persons living with life-threatening illness. They were soon joined by several more Catholic systems and CHA to form Supportive Care of the Dying: A Coalition for Compassionate Care.

The truth was, though, that all hospitals, not just Catholic ones, were affected by widespread inadequacies in, and misunderstanding about, end-of-life care. Studies such as one conducted by George Washington University, contributed to public fear and concerns. That study, published in the April 15, 1997, issue of *Catholic Health World*, showed that about 40 percent of dying patients die in pain, and nearly half are put on ventilators, fed through a tube or subjected to traumatic cardiac resuscitation procedures, in the last days of their lives. The researchers further found that nearly 59 percent of dying patients preferred a treatment focused on comfort, and 10 percent were receiving more aggressive care than they wanted.

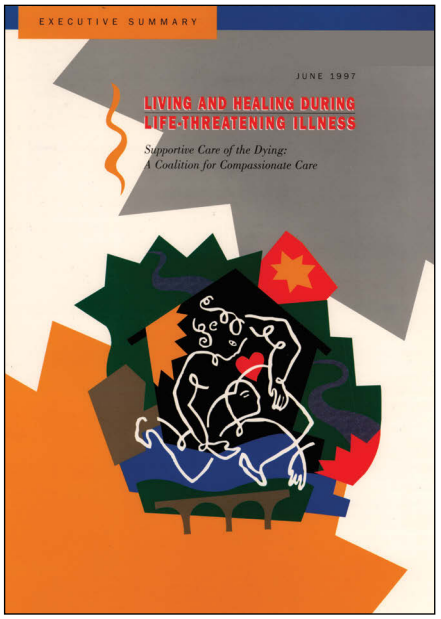
At the June 1997 Catholic Health Assembly in Chicago, the findings of the comprehensive research project con-

ducted by Supportive Care of the Dying were released in a moving session. The research team had interviewed more than 400 people in 55 focus groups in 11 cities across the country, eliciting the perspectives of dying persons, their families and caregivers. Speakers in the session challenged Catholic health care providers to radically transform end-of-life care. One of the presenters, CHA ethicist Ann Neale, said, "Our mission and values demand that we be remarkable in the ways we keep company with and care for those living the journey of life-threatening illness. In fact, who is better prepared than the Catholic health care ministry to serve as the change agent in this cultural transformation?"

CHA's ethicist Ann Neale participated in a panel discussion on the research conducted by Supportive Care of the Dying at the 1997 Assembly.

In succeeding years, CHA and its members took the lead nationally to usher in an era of expansion of palliative and hospice care with resources, standards and programs. Hospice benefits under Medicare had improved in the late 1980s, and by the early 1990s, hospice was widely accepted as part of the continuum of care. CHA strongly encouraged members to integrate hospice care into their facilities.

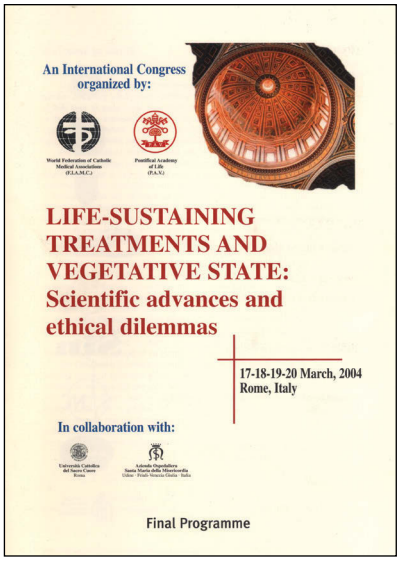
In time, the coalition released new measurement tools aimed at helping organizations assess performance and develop standards for care.



On the legislative front, CHA would continue to strongly oppose euthanasia and physician-assisted suicide and support the coalition in seeking to eliminate restrictive laws that prevented physicians from prescribing adequate pain medication.

In 1997, CHA joined other major medical and geriatric groups, including the American Medical Association, the American Association of Retired Persons and the National Council on Aging, in endorsing 10 principles for improving quality of care for dying persons. The organizations called for efforts to enhance patient functioning, increase patient and family control over decision-making, work with families to reduce health care costs, control pain, respect spiritual growth and better train physicians and other medical professionals.

By 1998, there were 13 Catholic health care systems with facilities in 49 states that had joined the coalition. Now known as the Supportive Care Coalition: Advancing Excellence in Palliative Care, it has continued to expand both in members and strategic goals.



ONGOING MEDICAL-MORAL CONTROVERSIES

The changes in federal law that had been precipitated by the Karen Quinlan and Nancy Cruzan cases left unresolved questions about Catholic teaching on the use of medically administered nutrition and hydration for persons in a persistent vegetative state. Addressing a continuing debate in Catholic bioethics that went back to the early 1980s, CHA was deeply involved in dialogue with Catholic theologians and bishops who had varying views on life-sustaining treatments in such cases. Some took the position that withdrawing a feeding tube was morally permissible; others contended it was not.

Traditional Catholic teaching had allowed for persons to forgo medical interventions based on a benefit-burden analysis. This was explained in Directive 57 of the 1994 *Ethical and Religious Directives*: "A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the judgment of the patient do not offer a reasonable hope of benefit or entail an excessive burden or impose excessive expense on the family or the community."

Directive 58 held that the benefit-burden analysis also applied to feeding tubes. It stated: "There should be a presumption in favor of providing nutrition and hydration to all patients including patients who require medically assisted nutrition and hydration, as long as that is of sufficient benefit to outweigh the burdens." Then the case of Terri Schiavo erupted into the public debate. Schiavo was a married woman whose parents opposed her husband's petition to have her feeding tube removed eight years after she lost consciousness in 1990 and lapsed into a persistent vegetative state. The prolonged legal battle continued from 1998 until 2005, when Schiavo died shortly after her feeding tube was finally removed. Widespread public discussion and concern in the U.S. and around the world prompted Pope John Paul II to deliver a papal allocution, or clarifying statement, in March 2004 titled "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas." In it, he said that food and water, even when medically administered, are not to be considered medical treatment, but rather, basic care. Therefore, the pope said, feeding tubes were morally required in virtually all cases and not subject to a benefit-burden analysis.

In response to the many inquiries from the ministry and the media about the Schiavo case, and concerns that confusion over the papal allocution would fuel the euthanasia movement, CHA released a variety of online resources. These included a Q & A on the allocution, further questions for study and discussion, a concise explanation of the church's teaching on life-sustaining treatment, a comparative analysis of past church teaching on nutrition and hydration and what the papal allocution said.

CHA posted a statement on its website advising members that further dialogue would be needed to determine the practical implications of the allocution for delivery of Catholic health care. Meanwhile, unless bishops directed otherwise, the 1994 *Ethical and Religious Directives* remained in effect. That included Directive 58, which called for a presumption in favor of nutrition and hydration to all patients, including those who

Fr. Albert S. Moraczewski, OP, PhD, president emeritus, The National Catholic Bioethics Center, and Sr. Carol Keehan, DC, CHA president and chief executive officer, participate in a table discussion at the 2006 CHA-sponsored "Dialogue on Medically Administered Nutrition and Hydration."

require it be medically administered, "as long as this is of sufficient benefit to outweigh the burden involved to the patient."

Within the ministry, discussions revolved around the allocution's implications for Catholic health care and how it should be interpreted in light of prior church teaching. In 2005, U.S. bishops requested clarification from the Vatican (in the form of a *dubium*) on several ethical questions raised by the pope's statement.

In a December 2005 audio conference for ethicists and others in the ministry, Ron Hamel, PhD, senior director of ethics at CHA since 1998, referred participants to Directives 56 and 57 for a summary of the church's traditional teaching and said that major church documents, such as the "Declaration on Euthanasia" issued by the Vatican's Congregation for the Doctrine of the Faith, and John Paul II's 1995 encyclical *Evangelium Vitae* should be consulted when questions arose, while giving consideration, but lesser weight, to the 2004 papal allocution.

In 2006, in an effort to navigate these murky waters, CHA sponsored a major conference titled "Theological Dialogue on Medically Administered Nutrition and Hydration." Participants, representing Catholic health care and the U.S. Conference of Catholic Bishops, explored related questions with the goal of achieving mutual understanding of various positions.

The Vatican's response to the bishops' *dubium* came in 2007, leading to a decision by U.S. bishops to revisit and later revise Directive 58 and intensifying claims by Catholic health care's opponents that Catholic hospitals would be unable to honor advance directives. The revised Directive 58, which gave rise to the Fifth Edition of the *Ethical and Religious Directives*, says there is a general moral obligation to provide nutrition and hydration, even when it must be medically administered, to patients, in a persistent vegetative state or other chronic condi-

2006

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tion. With regard to dying patients, the revised directive notes that nutrition and hydration are morally optional when deemed excessively burdensome to the patient or provide little or no benefit.

In 2007, CHA added to its bioethical resources for the ministry by assuming editorial responsibility for a quarterly publication, *Health Care Ethics USA*, with Ron Hamel as editor. Originally published through the Center for Health Care Ethics at Saint Louis University, the publication provided a forum for ethicists who wished to explore medical-moral issues in greater depth. Furthermore, it provided timely resources for ethics committees throughout the ministry.

Health Care Ethics USA

A resource for the Catholic health ministry

Ron Hamel, PhD

PRINCIPLES OF COOPERATION

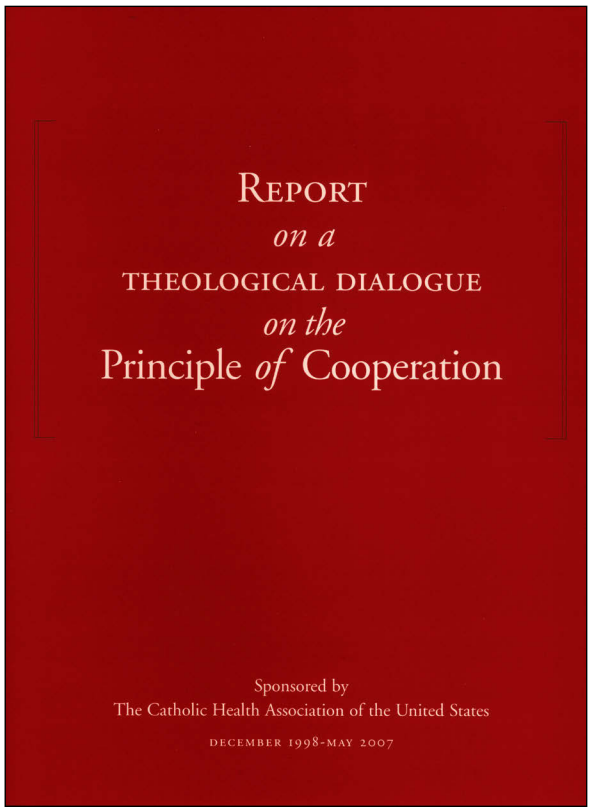
As health care evolved into increasingly bigger organizations in the 1990s and 2000s, collaborative ventures between Catholic and other-than-Catholic or secular organizations proliferated, bringing new opportunities and challenges. They could be as simple as joint ownership of technology or as complex as co-sponsorship of an integrated delivery or managed care network. Some arrangements, perhaps critical to the survival of the Catholic health ministry in a given area or providing a greater continuum of care, necessarily involved arrangements with partners engaged in activities deemed morally unacceptable by Catholic teaching. Primarily these involved provision of contraception and sterilization. Abortion, physician-assisted suicide and euthanasia, considered to be graver evils, were never regarded as an option in any form in collaborative venture.

Here, as with questions of medically administered nutrition and hydration, the ministry turned to the church's theological tradition for moral guidance. The tradition had for centuries provided guidance on questions related to "cooperation with evil": that is, how to assess wrongdoing when a person pursuing a moral good is assisted by another party engaged in committing a moral evil. However, applying what came to be called the "principle of cooperation" to business arrangements was new.

Acknowledging the moral complexities of the new relationships, U.S. bishops included in the 1994 *Ethical and Religious Directives* a new Part Six, called "Forming New Partnerships with Health Care Organizations and Providers." It was followed by an appendix titled "The Principles Governing Cooperation," which distinguished between the theological concepts of for-

mal and material cooperation and introduced the concept of "duress" as a possible justification for material cooperation in wrongdoing, such as providing contraception or sterilizations.

An early resource for interpreting the six entirely new directives in Part Six was a handbook for bishops and Catholic health care sponsors and administrators published in 1995 by the National Coalition on Catholic Health Care Ministry: *Catholic Health Ministry in Transition: A Handbook for Responsible Leadership.*



Within a short time, however, intense debate ensued over both the guidance provided in the *Directives* and interpretations in the manual, and CHA initiated a conference to search for common ground. In 1998, Fr. Michael Place, then president of CHA, convened an invitational gathering of interested bishops and theologians who held divergent views. The theologians represented academia, health care and the church. A hope held by ministry leaders, particularly sponsors and administrators, was that discussion and clarification would result in greater consistency when bishops were called upon to approve cooperative arrangements in their individual dioceses.

One significant sign that the meeting had been successful in clarifying some misperceptions and demonstrating significant areas of common ground came several months later, in May 1999, when the National Conference of Catholic Bishops' Committee on Doctrine requested that the dialogue continue, with a focus on specific questions that had come before the committee.

Of particular concern was a request by the Vatican's Congregation on the Doctrine of the Faith for revision of some of the specific directives in Part Six, and of the more technical appendix and its discussion of duress. Ultimately, the process led to a decision by the bishops to again revise the directives. They published a Fourth Edition in 2001, eliminating the appendix, adding two new directives to Part Six (Directives 70 and 72) and expanding Directive 71.

The CHA-sponsored theological dialogues reconvened in 2001 and continued through 2005. A final report identifying the main areas of agreement and disagreement was disseminated across the ministry and distributed to U.S. bishops in May 2007.

The result was that, in new cooperative arrangements, duress no longer provided a justification for material cooperation in forbidden practices. Catholic organizations now took pains to distance themselves from any engagement with forbidden procedures such as sterilizations or tubal ligations. Instead, the process allowed for "carve-outs," i.e., organizations entirely separate in sponsorship, administration and all functions, from the main collaborating organizations.

1994

A prolonged controversy began over which medications were morally permissible and what kind of testing was needed to ensure that the forbidden effects under Directive 36 would not occur.

OTHER ETHICAL CONCERNS

After the Federal Drug Administration approved levonorgestrel, or Plan B, for use as a post-coital contraception, or "morning-after pill," in 1999, it soon became the clinical protocol of choice for preventing pregnancy from rape. In theory, the *Ethical and Religious Directives* allowed medications for preventing pregnancy to occur. Directive 36 of the 1994 edition states that a woman who has been raped "should be able to defend herself against a potential conception from the sexual assault." If appropriate testing gives no evidence that conception has occurred, "she may be treated with medications that would prevent ovulation, sperm capacitation or fertilization," but treatments "that have as their purpose or direct effect the removal, destruction or interference with the implantation of a fertilized ovum" are not permitted.

Thus began a prolonged controversy over which medications were morally permissible and what kind of testing was needed to ensure that the forbidden effects under Directive 36 would not occur. The most scrutinized medication was Plan B, based on numerous studies showing that it acted as a contraceptive and not an abortifacient — that is, it prevented fertilization if administered in time, but had little to no effect once fertilization occurred. However, the medication's physiologic mechanism was highly controversial in some quarters. CHA met with the U.S. bishops' Committee on Doctrine to explore related scientific and moral questions. Ultimately CHA ethicists determined that, based on numerous studies showing that Plan B was an unlikely abortifacient, its use was justified under the theological principle of "moral certitude" for use in Catholic hospitals as an emergency treatment for rape. CHA opposed the "Peoria Protocol" (so-called because it was required for Catholic hospitals in the Diocese of Peoria, Ill.), which called for delaying administration of Plan B until very specific and technical laboratory testing showed ovulation had not occurred.

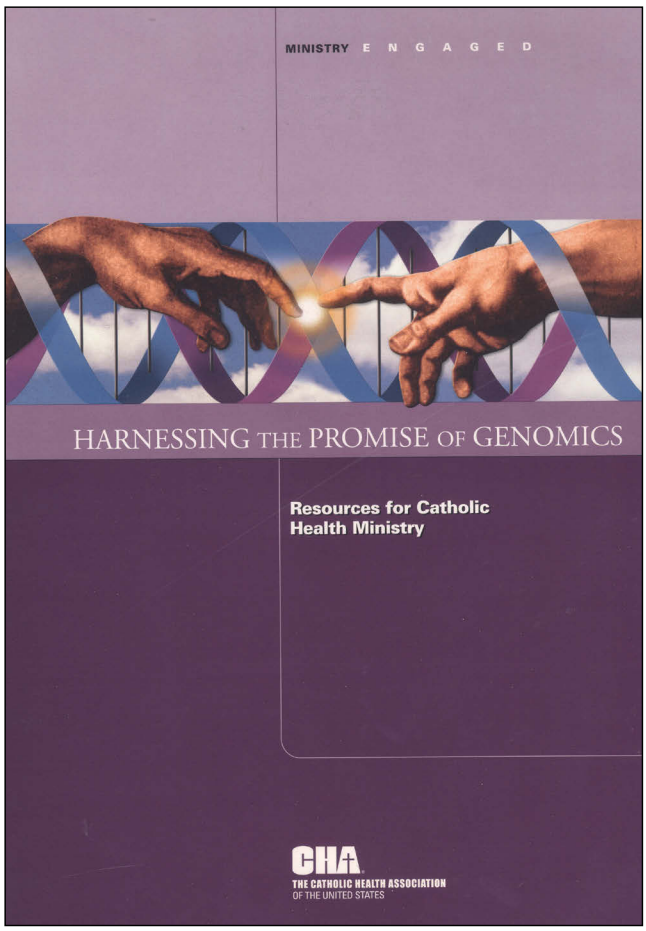
CHA, which continued to update the ministry through advisories and articles in *Health Progress* and *Health Care Ethics USA*, argued that the required tests under the Peoria Protocol were overly rigorous, difficult to administer on short notice and morally unnecessary; they also were lacking in the compassionate, pastoral approach called for in Directive 36.

By the mid- to late-2000s, Plan B had been accepted in most Catholic hospitals as standard care for female victims of sexual assault, though some confusion and controversy remained.

Other bioethical controversies prevalent in the 1990s and 2000s were primarily related to genomics and stem cell research. A major impetus for the former was the announcement in 1990 of the Human Genome Initiative, an international re-

search project sponsored by the Department of Energy and the National Institutes of Health and aimed at mapping and sequencing the entire human genome.

CHA's role in these issues was for the most part educational, keeping members updated on new developments in genomics and exploring related ethical questions in colloquia, articles and webinars. In these areas, questions often had to do with health care in general rather than to Catholic health care specifically. The exceptions were growing use of amniocentesis to determine fetal abnormalities and research on stem cells taken from human embryos.



Amniocentesis was a prohibited procedure in Catholic teaching if the intent was to abort an abnormal fetus. Embryonic stem cell research was forbidden under the church's ban on abortion, although research on adult stem cells with an eye to preventing or curing illnesses was welcomed.

The questions related primarily to what kinds of genetic information should be divulged and to whom, and to concerns about discrimination and privacy.

Among the resources developed for members, CHA's "toolkit" titled "Harnessing the Promise of Genomics" was one of the most substantial. It included two booklets, one exploring the theological foundations for the church's engagement with genetic research, the other providing a summary of Catholic teachings on science and genetics.

Bioethical issues and numerous social issues requiring ethical analysis are likely to continue to generate discussion and controversy into the foreseeable future. The need for resources to educate and support the Catholic health ministry in the pursuit of clarity in ethical dilemmas and good practices remains one of CHA's most important responsibilities.

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