Volume 23, Number 1 ■ Winter 2015

Health Care Ethics USA

A resource for the Catholic health ministry

In This Issue

FEATURE ARTICLE

Bioethics Questions & Controversies

Editor's note: This article is reprinted from the January-February 2015 issue of Health Progress for the benefit of those who may have missed it in Health Progress.

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The advent of 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, publicity over 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reasonable hope for recovery -- and both sets of parents were blocked in seeking to have life-sustaining interventions withdrawn.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 in 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 also 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 treatment, including treatments intended to forestall death.

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 were existed.

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 to 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.

The educational efforts included conferences and presentations 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 ethical and legal dimensions of the law.

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."

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, Ph.D., 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 a straightforward list of directives, as in the 1971 edition, the revised document was divided into six sections, each beginning 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.

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 for patients who too often experienced poor management of their pain. Complaints emerged, too, over neglect of the psychological, social and spiritual needs of patients and their families, who often suffered severe emotional and financial burdens. Public acceptance of physician-assisted suicide and euthanasia was growing nationally, 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 conducted 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?"

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 from 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 26-year-old 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, widely publicized, legal battle continued from 1998 until 2005, when Schiavo died shortly after her feeding tube was finally removed. The 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 were 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 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 pope's statement.

In a December 2005 audio conference for ethicists and others in the ministry, Ron Hamel, Ph.D., 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, giving rise to a decision by U.S. bishops to revisit and later revise Directive 58 and intensifying claims by opponents of Catholic health care 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 condition. However, the revised directive notes that with regard to dying patients, 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 new 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.

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 formal 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 that identified 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.

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 as an abortifacient -- that is, it prevented fertilization if administered in time, but had little to no effect once fertilization had occurred. However, the medication's physiologic mechanism was highly controversial in some quarters, and 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 not only were overly rigorous, difficult to administer on short notice and morally unnecessary; they were lacking in the compassionate, pastoral approach called for in Directive 36.

By the mid- to late-2000s, Plan B had been well 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 research 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 related to 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.

FEATURE ARTICLE

'Tolerance' as a Moral Concept for Catholic Health Care Ministry in a Pluralist World

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Introduction

"Healthcare in the United States is marked by extraordinary change." This is the opening sentence of the *Ethical and Religious Directives for Catholic Health Care Services (ERDs)* as revised in the early 1990s. It is a statement that has not needed to be modified in the subsequent editions of the *ERDs* as extraordinary structural change seems to have increased in velocity.

In the last 50 years, stand-alone hospitals developed into health care systems to survive, and small systems often joined together. Moral theologians responded to the wave of hospital mergers and acquisitions by use of the long-standing analytic framework of cooperation with evil. Cooperation review had been present, of course, in clinical practice and was modified from its original application for individual persons and events to the hospital structures themselves in Catholic health care ministry.

At present, merger activity continues, but a more fundamental re-imagining of the structure of health care is underway. Perhaps there is a shift from a "component" view (i.e., acute care facility, medical group, rehabilitation services, home health and hospice services) of the health care system to a continuum of care. In the component model, the "health care system" usually owned all the pieces, whereas, the continuum model will probably be too big and too complex for system ownership.

A continuum will often be assembled by an entity, such as a governmental agency or insurance company that holds health care contracts for segments of an area's population. Many Catholic health care systems have contracts with insurers to provide elements of medical care to persons who are insured by health plans. A continuum of care is not built with brick and mortar but by contracts.

One moral question that emerges with the developing paradigm is the way Catholic health care ministries might be able to structure significant parts of the continuum of care. How will the ministry view and engage a range of potential partners who may share with us common values in a vision of health care, but are neither formed by the Gospel vision of service nor adhere to Catholic moral teaching and the *ERDs*?

Of course, cooperation analysis will continue to be used in future discernment. This article proposes that "toleration" is an equally well-established theological way of responding to real life situations and understanding aspects of responsibility

and action. The article will examine the term based on its use in the writings of St. Thomas Aquinas in the *Summa Theologiae* and its application to health care, particularly in light of participation in the emerging continuum.

In *Evangelii Gaudium* / *The Joy of the Gospel*, Pope Francis writes, "When we read the Gospel we find a clear indication: not so much our friends and wealthy neighbors, but above all the poor and the sick, those who are usually despised and overlooked" are to be the first attention of the Church.[1] This call from the poor and the sick is ever-present to Catholic hospitals in the United States from their immigrant roots. Increasingly, service to the poor and the sick will be found in 21st century contracts for "population medicine" and in the continuum of care. It seems that this is a path the health care ministry must take.

Catholic Health Care's Foundation

Service is a demand of Christian discipleship, a Gospel call transmitted by the Church, expressed in the "mission" of Catholic health care. We respond to the Gospel call to "go and do likewise" (*Lk.* 10) to the persons of our time, whom we understand as our sisters and brothers in the Lord, persons beloved by God-Trinity.

In his important inaugural encyclical, *Deus Caritas Est*, Pope Benedict XVI turns to the "great parable of the Last Judgment (cf. *Mt* 25:31-46), in which love becomes the criterion for the definitive decision" of a person. The Pope concludes the section stating that "love of God and love of neighbor have become one: in the least of the brethren we find Jesus himself, and in Jesus we find God."[2]

In *Deus Caritas Est*, Pope Benedict wrote that "two essential facts emerged" in the course of his teaching. The first is the presence of the ministry of charity in the heart of the Church: "The Church's deepest nature is expressed in her three-fold responsibility of proclaiming the word of God (*kerygma-martyria*), celebrating the sacraments (*leitourgia*), and exercising the ministry of charity (*diakonia*). These duties presuppose each other and are inseparable. For the Church, charity is not a kind of welfare activity which could equally well be left to others, but is a part of her nature, an indispensable expression of her very being."[3]

Pope Benedict does not isolate the three elements, but shows they are dynamically related: "Faith, worship and *ethos* are interwoven as a single reality which takes place in our encounter with God's *agape*." The Pope writes in stark terms: "Here the usual contraposition between worship and ethics simply falls apart. 'Worship' itself, Eucharistic communion, includes the reality both of being loved and loving others in turn. A Eucharist which does not pass over into the concrete practice of love is intrinsically fragmented."[4]
The second half of the encyclical makes explicit application to care of the sick, and finds it an abiding and essential element of the life of the Church, an application of *diakonia*.

Pope Francis, in a recent visit with bishops of Zambia, pointed to Catholic schools and hospitals as fruits of the rootedness of the faith in that nation. The Pope called out the "plentiful spiritual harvest evident in the many Catholic-run clinics, hospitals and schools and parishes throughout Zambia, a wide diversity of lay ministries, and substantial numbers of vocations to the priesthood in a society that has been transformed by Christian values."[5] In this list, the Pope gave a very early recognition to Catholic clinics and hospitals and celebrates them as part of a "plentiful spiritual harvest," rather than as an organizational structure. A vision of Church ministries as a fruit of the life of faith is an opportunity for moral analysis, a foundation for discernment of pathways and engagement.

Pope John Paul II gave ongoing support and guidance to Catholic health care ministries and Catholic physicians and nurses in the course of his pontificate. Among other topics, he repeatedly called for a "humanization of medicine" so naturally arising from his personalist philosophy. The Pope saw this humanization as a pressing contemporary need because despite progress in curative medicine, the reality of sickness and mortality remains. There is a great risk, the Pope told a religious institute devoted to hospital ministry, that the sick could be "marginalized" and clinicians see their work as "becoming a job." The people of Catholic health care "are called to "humanize" treatment of the sick, and to see the sick person as a creature of God, a brother in Christ."[6]

Tolerare, Toleration in the Catholic Tradition

As care for the sick is a Gospel mandate, Catholicism has a long and impressive tradition of engaging with the clinical situations of persons who are the reason for this ministry in the context of the political and social realities of the time. A range of styles of theological reflection for engagement has developed in theologies of *praxis*. Theological *praxis* looks for ways Gospel ministries can continue to respond to God's call in the needs of our brothers and sisters. Theological *praxis* has significantly expanded from clinical response to ministry structure.

"Cooperation with evil" analysis, often referred to as "cooperation analysis" has been an essential resource for engagement by Catholic moral philosophers and theologians. While first and classically used to address cases of individual moral actors, cooperation has been heavily used in the analogous application to institutional arrangements of various kinds.

As "cooperation" is a resource that has been retrieved from well-established use in theological analysis, this article proposes recovery of an ancient term in Catholic theology, that of toleration (*tolerare*) of evil. The two, cooperation and toleration, can accompany each other as resources for analysis.

Perhaps we should first address the word 'tolerate' in current English language usage to address any barriers in our language that could impede a recovery of

'tolerate' in theological usage. A significant barrier to understanding theological toleration would be primarily equating the term with a philosophy of relativism or nihilism, in which the absence of meaning demands an equal status for all points of view that are not offensive to public attitudes. This use of toleration is present in philosophy in recent centuries, and so it is important to air this concern. However, such usage is neither the classical nor leading contemporary meaning. In fact, while it is necessary to recognize the relativist use of toleration, it would be a mistake to lose a classical term in our ecclesial lexicon.

Turning to the multi-volume *The Oxford English Dictionary* (*OED*) is like a visit with the history of the language. *OED* finds "tolerate" coming into English use from 15th century French, and from the Latin *tolerare*, which it translates as "to bear, endure."[7] The underlying Latin meaning of bearing with or enduring something remains the common and current use of "tolerate."

The first meaning *OED* gives to tolerate is "to endure, sustain (pain or hardship)" which was first found in 16th century English use[8] and is also applied in the 19th century to "endure with impunity or comparative impunity the action of (a poison or strong drug)." The second meaning is also found in 16th century use: "To allow to exist or to be done or practiced without administrative interference or molestation…to allow, permit." When toleration was used by rulers it did not signify approval of a range of social phenomena (heretics, usury and prostitution are longstanding examples), but the relative inability to control them with resources available, and was utilized in situations by Catholic monarchs and the Papal States. The third meaning is "to bear without repugnance; to allow intellectually, or in taste, sentiment; to put up with."

Our English language sense of toleration as enduring or bearing with the difficult is quite the same as the 13th century theological use of the term by St. Thomas. Yet, the classical Christian "world view" of St. Thomas available to us, of course, was shaped by God's active self-giving (grace) for human response in time for the sake of consummation in the eternal communion of Trinitarian love. In the matter of human actions, Thomas readily saw us moved by some sense of the good, but one that could be flawed or misbegotten. However, the presence of humanity's failings does not thwart God's healing and elevating work. Thus, Thomas could be very realistic about flawed individual or social actions and yet would expect the Church to continue its proper work and witness in the midst of it all. St. Thomas' use of toleration arises from his reception of it from earlier Christian theologians, in a manner so typical of the Catholic theologian—to first be a listener in the theological conversation that has preceded us and to sustain and perhaps develop it, in reliance on the gifts of the Holy Spirit.

Tolerare appears eleven times in the *Summa Theologiae* and on numerous other occasions in different verb tenses. *Tolerare* itself demonstrates the manner in which St. Thomas uses it for purposes of this

essay. In the 1947 Benziger (1920, Blackfriars) edition, *tolerare* is primarily translated as "bear with" and "endure." It appears four times each and accords with the *OED* usage. "We ought to suffer them with equanimity" appears once, "suffer" being a quaint or archaic manner of stating "bear with" or "endure."[9]

St. Thomas quotes *tolerare* in citing St. Augustine and St. Gregory the Great, further establishing and validating the ongoing use of *tolerare* from very early Christian theological usage. Beneath it all, *tolerantiam* appears as "endure" at 2 Cor. 6 in the Vulgate: "…if we are being consoled, it is for your consolation, which you experience when you patiently endure the same sufferings that we are also suffering."[10]

An important modern sighting of *tolerare* is in the encyclical of Pope Paul VI, *Humanae Vitae* (1968). In section 14, several contrary arguments to the encyclical are presented and dismissed, including that of overall totality of marital intercourse that is open to conception. In the midst of this discussion is this classical moral statement: "Though it is true that sometimes it is lawful to tolerate a lesser moral evil in order to avoid a greater evil or in order to promote a greater good, it is never lawful, even for the gravest reasons, to do evil that good may come of it."[11] Its use by Pope Paul VI suggests the continued availability of this term for moral discourse in our time, following the example of early Christian writers through St. Thomas to us.

Theological Analysis

A recovery of moral toleration may be particularly helpful in the present stage of health care transformation in the United States as the continuum of care, which can include many distinct health care organizations, is being developed.

Toleration's new usefulness is timely as the word "collaboration" gains prominence in Catholic moral discourse: collaboration to find opportunities to offer needed health care services in the continuum of care while addressing the moral risks to the Catholic health care ministry. New attention was rightly given to collaboration with the release of a February 17, 2014 letter and document from the Congregation for the Doctrine of the Faith (CDF) to Archbishop Joseph Kurtz, president of the United States Conference of Catholic Bishops (USCCB).

The CDF letter from Cardinal Gerhard Muller, Prefect of the Congregation, states that the question presented to the CDF by the USCCB in 2013 was specifically regarding a particular arrangement, but the CDF thought it best to provide a series of principles to guide arrangements between Catholic and other-than-Catholic health care organizations. *Some Principles for Collaboration with Non-Catholic Entities in the Provision of Healthcare Services* (*Principles*) begins with a significant theological location of care for the sick as a "prophetic witness to the Faith" and an "evangelical spirit." It notes that while care of the sick always presented clinical moral questions, new

issues regarding the structure of health care services itself require response.

Health care organizational structures exist to fulfill the Gospel mandate. Thus, they are neither ends in themselves nor can they be understood outside of the context of Gospel response. The prologue of *Principles* quickly states its understanding of the present health care environment: "In today's world…effective engagement in healthcare often calls for collaboration with non-Catholic healthcare institutions, even establishing joint working arrangements in which the Catholic and non-Catholic entities are full partners."

An important and very traditional point follows: "In itself, collaboration in good works is, of course, a good thing…." The remainder of the sentence draws attention, as is required in a vigilant spirit, to the danger of potential involvement with various degrees of "institutional connections with activities that conflict with the natural law and Church teaching." Collaborative relationships require that Catholic health care governance must "ensure that the witness of the Church is not adversely affected" and that these relationships do "not give scandal."

Seventeen principles that apply the Principle of Cooperation to various types of arrangements with non-Catholic health care entities follow the prologue. These principles both restate existing principles of licit and illicit cooperation with non-Catholic health care entities and specify applications of these norms to the recent phenomenon of system mergers.

Principles closes with a final positive use of the word "collaborate" to call Catholic health care systems to collaborate with the bishops of all the dioceses in which their facilities serve persons.

Principles creates a timely recognition of the positive meaning of "collaboration in good works." It prompts a fresh reading of the Introduction to the *ERDs* Part Six—Forming New Partnerships with Health Care Organizations and Providers—with its notice and support of collaborative efforts for prophetic Catholic witness to its dedication to the health care ministry and health care professionals; to "implement the Church's social teaching"; "to realign the local delivery system in order to provide a continuum of health care; to manifest "a responsible stewardship of limited health care resources", and to develop "a more equitable access to health care" for poor and vulnerable persons.

Collaboration also receives support and encouragement from Pope Francis who writes of the importance of "feeling close to" and respectful of engagement with "those who do not consider themselves part of any religious tradition" and strive toward truth and goodness. This spirit has specific application to hopeful engagement with a pluralist continuum. "We consider them as precious allies in the commitment to defending human dignity, in building peaceful coexistence between peoples and in protecting creation."[12]

As used by Pope Francis, "coexistence" can even be applied to rightly understood

participation in the pluralist health care continuum of care. Coexistence evokes our understanding of toleration and can be a significant term for moral theology. Looking to the future, coexistence can be based on the lived pastoral experience of "*tolerare*" as its platform for further development.

Coexistence in the writings of Pope Francis is also a prompt for common efforts for justice and peace. When disparate individuals and groups work together, opportunities for Church witness to the Lord and the life of faith can arise. Coexistence should call us to a more intense Christian ministry rather than a reduction to the lowest common denominator.

In those health care system relationships in which illicit cooperation is not an issue, collaboration in the good is freely available. When the potential partner in the continuum of care or in a joint venture is a non-Catholic entity, toleration can be an effective and principled response. Toleration is a way to live with the moral otherness of a partner that has common moral goals and practices. Toleration does not mean endorsement of practices taught as immoral by the Church. Coexistence is the recognition of pluralism and the freedom for the Church partner to witness to our faith.

A contemporary Catholic understanding of toleration and moral growth is found in philosopher Martin Rhonheimer, who states that only in the light of faith can the fulfillment of the person and understanding of moral life appear in an integral manner. "This leads us to an attitude of understanding and tolerance, not of sin, but of the persons who feel unable to fully meet the requirements set forth in the Church's moral teaching."[13] Rhonheimer continues, "Without relativizing or unduly adjusting the "ought" to the "can" or graduating the moral norm, all pastoral work nevertheless has to try to gradually lead each person to fulfill all the good toward which their human nature, redeemed by Christ, aims."

Of course, St. Thomas did not live in an era characterized by our pluralism. But Thomas paid great attention to the meaning of good actions done in a collaborative spirit and the need for virtuous practice (prudence, justice, temperance and fortitude) to sustain the good envisioned. How would he see toleration employed in a continuum of care to effect greater health of a community with a range of Catholic and non-Catholic entities who share a general moral vision, but hold a range of specific moral positions at variance with one another?

St. Thomas is likely to affirm pursuit of the good if the consciences of the member organizations are protected in structure and practice. Toleration could be used when there are no demands for the Catholic ministry to either do evil or partner for the performance of specific evil actions. Membership in the continuum in which evil acts are present but without any involvement of the Catholic party should not be seen as cooperation in those acts.

My proposal that presence in a continuum of care with illicit procedures present in it does not in itself constitute material or formal cooperation may be somewhat controversial to some moral theologians or moral philosophers in the United States. I do not believe the proposal would be a surprising one to theologians who studied or practiced in Rome in the mid-twentieth century. Two reasons come to mind: first, they would likely be aware of St. Thomas' use of *tolerare* and, second, the Roman perspective was one in which observation of manifold new applications of secularity in post World War II Europe was tolerated.

One example in the mid-twentieth century would be the rise of comprehensive social welfare programs in Western Europe in which Church ministries had to find new roles and often accepted public funding for their ministry. Another would be the problem of Church persecution in Communist regimes. The Roman observer would see clearly what local churches had to endure, tolerate and bear. Their struggles were seen as acts of fidelity and witness. Particular churches used their opportunities to do the good they could do in a range of settings and to accept the social realities for what they were.[14]

Toleration in the evolving health care continuum in this nation would have the following elements: appreciate the members of the continuum for the good they do; welcome progress in the good envisioned; prioritize care of the poor and marginalized; learn from other members how to improve the care given by the ministry; mourn the lack of moral vision by all members; effectively separate the ministry from planning, contracting, performance of or receipt of funding related to immoral procedures; educate patients about the scope of Catholic ministry; and develop ministry colleagues for ministry vitality and integrity.

Toleration would welcome doing good, respect of partners, and the ongoing and dedicated work of external information and internal education. Presence in a pluralist continuum of care would require, in a word, hope of the good and "bearing with" the specific new work required of the Catholic entity for collaborative participation in the pluralist continuum.

Participation in a continuum of care does not in itself signify cooperation with evil, and thus it is essential that the Catholic entity is effectively separated from immoral actions and identified as such. Collaboration, with a tolerance, cooperation and scandal review process, can be a framework for envisioning a good work together.

A "statement of common values" can be helpful for the internal culture of collaborative partners to state the common ground and goals they share. Catholic health care parties can take a lead in this conversation if the ministry has a mission-based culture and naturally pays heed to its culture and values.

Collaborative processes require that partners maintain their own identity. Such is critically important for the

Catholic health care entity, as it should be a good partner in meeting the needs of a population of persons and also maintain its own Gospel response and identity. Thus, internally and externally, persons know where the Catholic partner "begins and ends" in the continuum, while making its own contribution to a vibrant response to provide community medicine (covered populations) and community health (affirmative measures to support the health and wellness of communities).

At every stage of history, the Gospel call remains clear to those who have found discipleship and a transformed life in the Church: those we serve are our sisters and brothers and are neither "cases" of disease nor anonymous "populations." The Lord has identified himself with the most marginalized we serve (Mt 25:36) who are at the core of our prophetic witness. Thus, if collaboration is needed to meet the needs of the poor and underserved, it does not seem morally optional.

In *Deus Caritas Est*, Pope Benedict wrote that "*caritas-agape*" to meet the necessities of life is essential for the inner life of the Church and that it also "extends beyond the frontiers of the Church." The Pope follows this with a particular way of looking at persons, the second "essential fact" of *diakonia*: "The parable of the Good Samaritan remains as a standard which imposes universal love towards the needy whom we encounter "by chance" (cf. *Lk* 10:31), whoever they may be."[15]

"By chance" leads to reflection on experience and on the future. Persons who work in acute care facilities experience as normative that we never know who will come through the door for care. In the same way, the Catholic health care ministry can be drawn close to those who "by chance" appear within future populations for care, and strive to carry Jesus' great command of love to unique persons within population groups.

Engagement with other health care entities can be difficult for health care leadership in the United States. A competitive experience and anti-trust laws and regulations inhibit an instinct of collaboration. However, three factors are signs of a new hope for meaningful collaboration: 1) the development of the continuum of care to provide "population medicine"; 2) recent federal government approval for health care institutions to pursue community health activities (providing no anti-trust standards are violated); and 3) the rising expectation of health and wellness measures by a wide range (beyond health care entities) of community leaders to initiate community health initiatives.

Conclusion

In conclusion, it was the modest hope of this paper to re-introduce the use of toleration. Collaboration may require toleration of other entities and expects that they would tolerate us as well. The health care environment today is highly stressed for persons at every level of the ministry. Health care structures and their financing are being rebuilt around us. It is a time of trial to build the future while caring for persons (and each other) in the present and while heeding the discipleship

call that is ancient and renewed in the moment of encounter.

Collaboration in the good is the work of peace, reconciliation and development. Catholic ministries should enter into this willingly, but in a humble manner as we may be learning much from other entities who are already present in this field.

Our present cultural environment is often one of a profound "horizontalism" and loss of the transcendent nature of each person.[16] Committed engagement in building the new structures of health care can be an opportunity for the inner renewal of the Catholic health care ministry and a renewal of our interwoven love of God and neighbor. In a 2009 talk to Argentine bishops, Pope Francis stated that "the Holy Spirit leads us and guides us in two different directions: *inwardly*, as we enter into the mystery, and *outwardly*, to give us the strength to witness."[17]

Pope Francis encourages hope in dedication to the needs of the poor and that the Church witness to conversion from a culture of waste and indifference to a culture of encounter and accompaniment. Committed to God and continuing our tradition of service, we can continue to find new ways to serve persons in their health care and human needs (which includes our human transcendent reality) and confidently participate with persons of goodwill in our time.

Pope Francis writes "….Our dream soars higher. We are not simply talking about ensuring nourishment or a 'dignified subsistence' for all people, but also their "general temporal welfare and prosperity. This means education, access to health care, and above all employment…."[18]

As health care is restructured in the nation, we have our work ahead: responding to the call of Jesus in unique vulnerable persons, particularly in the poor, and stewardship of the ministry in transition. Ministry founders have taught and witnessed that our work is sustained by personal encounter with Jesus and the gift of the Holy Spirit. The particular steps ahead for health care are not fully known or clear, but we can have a common heart with the sisters and other religious founders of health care ministries that our generation is called to continue.

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[1] Pope Francis, *The Joy of the Gospel / Evangelii Gaudium*, 2013. Sec. 48.
[2] *Deus Caritas Est*, 2005. Section 15.
[3] Op. cit. Section 25.
[4] Op. cit. Section 14
[5] Pope Francis, "To the bishops of Zambia: evangelize cultures to inculturate the Gospel." Vatican Information Service, 17 November 2014, Year XXII, Num. 202.
[6] Pope John Paul II, "Discorso di Giovanni Paolo II ai Partecipanti al 61 Capitolo Generale dell'ordine Ospedaliero di San Giovanni di Dio." 17 December 1982.
[7] *The Oxford English Dictionary, Volume XVIII*. Oxford: Clarendon Press, 1989.
[8] Ibid., 1531, Elyot, "To tollerate those things whiche do seme bytter or greuous (whereof there be many in the lyfe of man)."
[9] The more recent (1960s-1970s) Blackfriars translation (ed. Thomas Gilby, OP) has a similar usage pattern: endure (four times); variations on "bear with" (three times); accept; tolerate and suffer (each once).
[10] New Revised Standard Version.

[11] The Latin text is: "*Verum enimvero, si malum morale tolerare, quod minus grave sit interdum licet, ut aliquod maius vitetur malum vel aliquod praestantius promoveatur, numquam tamen licet, ne ob gravissimus quidem causas, facere mala ut eveniat bona*." The Italian, similarly: "*…tollerare un minor male morale….*" Pope Paul's statement is very close to the toleration St. Thomas states as reasonable for government: "So, too, in human government, the authorities rightly tolerate certain evils lest certain goods be impeded or greater evils be incurred." *Summa Theologiae*, II-II, 10, a. 11, resp. (trans. Thomas Gilby, OP).

[12] *Evangelii Gaudium*. Section 257. This openness to others in themselves and for common action can occasion the important "reciprocity of conscience" described by Bernard Haring in *Free and Faithful in Christ, Vol. 1*, 264-270.

[13] Martin Rhonheimer, *The Perspective of the Acting Person: Essays in the Renewal of Thomistic Moral Theology*. Washington, DC: The Catholic University of America Press, 2008, 17.

[14] As Archbishop of Buenos Aires, Pope Francis spoke at a 2012 catechist encounter: "One must not take a selective attitude toward life as it comes to us, unlike the Scribes and Pharisees who murmured against Jesus: "This man receives sinners and eats with them" (Lk 15:2). Jesus received life as it was, not wrapped up in luxury packaging. "This is life, and I receive it," Jesus would say. It's the same with soccer: You have to accept penalty kicks wherever they come; you don't get to choose where anybody is going to kick them. Life comes at us like that; you have to receive it even if you don't like it." Pope Francis, *Encountering Christ: Homilies, Letters, and Addresses of Cardinal Jorge Bergoglio*. New Rochelle, NY: Scepter Press, 2013, 16.

[15] *Deus Caritas Est*. Section 25.

[16] Karl Rahner, "The Church's Commission to Bring Salvation and the Humanization of the World," in *Theological Investigations, XIV.* Trans. David Bourke. New York: Seabury Press, 1976.

[17] Pope Francis, *Encountering Christ*, 115.

[18] *Evangelii Gaudium*. Section 192.

Prophylactic Salpingectomy to Reduce the Risk of Cancer: Ethical Considerations

A Case

A 28-year-old patient is 25 weeks pregnant with her second child. She is scheduled for a C-section. She has two relatives who had ovarian cancer, one of whom passed away from the disease. She knows that this family history increases her risk of ovarian cancer.

Ovarian cancer grows slowly. Pre-invasive and early stage disease often go undetected. Many patients have malignancies more than four years before ovarian cancer is detected. By the time of diagnosis, the cancer is often advanced and aggressive growth has already occurred. As a result, the five year survival rate is only about 45 percent.

At her last appointment, the patient tells her OB that she read that removal of the fallopian tubes and the ovaries might help to prevent ovarian or breast cancer. The patient explains that she does not want removal of her ovaries, which will prematurely cause menopause; however, she asks whether she could undergo a risk-reducing salpingectomy (removal of the fallopian tubes) in conjunction with her C-section. She is very concerned about her risk of cancer and has become increasingly anxious about her health after the birth of her child. Although salpingectomy will cause sterilization, the patient accepts that she will not be able to have another child. She is most concerned about reducing her risk of ovarian cancer.

May a salpingectomy be performed in conjunction with a C-section to reduce the risk of cancer?

Ministry Perspectives

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Salpingectomy is a prophylactic, preventative or cautionary surgery to remove the fallopian tubes for women at high risk of ovarian cancer. Between 1 in 400 and 1 in 800 people in the U.S. population carry one of the causative mutations, and salpingectomy has become the "standard of care" in these cases.[1] Ovarian cancer is a significant issue in women's health and the overall survival rate at five years is only about 45 percent. For women with increased risk of ovarian cancer, the lifetime risk ranges from 16 to 54 percent, and often involves an increased risk of breast cancer. Last year actress Angelina Jolie chose to have a double mastectomy and reconstructive surgery after learning she had an 87 percent risk of breast cancer because she carries the BRCA1 gene.[2]

Ovarian cancer is not a single disease process arising on a single site or from a single cell type. The most common subtype has been identified as serous

(epithelial ovarian cancer), and the fallopian tube is often the first place of involvement. This subtype is most commonly found in BRCA1/2 mutation carriers[3] and up to 20 percent of these cancers occur in women with germ line BRCA1/2 mutations.[4]

A woman with BRCA mutations can chose risk-reducing surgery to excise her fallopian tubes and sometimes her ovaries (oophorectomy). When pathologically examined after surgery, about 10 percent of women undergoing salpingectomy were found to have an early cancer. The majority of early cancers were found in the distal fallopian tubes and not the ovaries. Due to its location in the fallopian tubes, the cancer metastasizes to the ovaries and surrounding pelvic structures.

While salpingectomy is standard medical treatment, is this surgery in line with Catholic moral teaching that places significant value on the preservation of the whole of the human person, stresses that a pathology must be present in order to remove an organ,[5] views mutilation of a healthy organ as intrinsically evil,[6] and condemns direct sterilization?[7]

Pope Pius XII delineates three conditions when it is permissible to remove a healthy organ:[8] the functioning organ is causing serious damage or constitutes a menace to the whole organism; clear evidence confirms that the damage will be remediated or measurably lessened by the mutilation; and the negative effects of mutilation will eliminate the danger to the whole, ease the pain, or secure positive effects.[9] In other words, a removal of a healthy organ removes the “field of growth" and dramatically diminishes the risk of life-threatening disease.

Regarding prophylactic mutilation, Pius XII stated that "by virtue of the principle of totality and the right to use the services of the organism as a whole, each person can permit individual parts to be destroyed or mutilated when the good of the whole requires it. This may be done to ensure life, as well as to avoid or, naturally, repair serious and lasting damage that cannot be otherwise be avoided or repaired."[10] Healthy organs, therefore, may be removed for the good of the whole whenever their functioning poses a physical risk. The decisive moral element is that the preservation of the organ or its functioning poses a direct or indirect threat to the body.[11]

Consequently, salpingectomy is morally permissible. Even though the surgery renders the generative faculty incapable of procreation, this is not its sole effect, or the primary intention. Rather, the act of removing the fallopian tubes (and sometimes ovaries) is in itself sufficient for a notable clinical benefit conferred directly to the patient and this constitutes the primary intention.

Categorizing salpingectomy a "drastic measure," National Catholic Bioethics Center's Director of Education Fr. Tad Pacholczyk draws a helpful distinction between the importance that the integrity and order of the human body be respected and not unduly violated (the Principle of Integrity) and whether or not an individual organ or part of the human

body may be sacrificed for the continued survival of the whole person (the Principle of Totality). Salpingectomy lies "somewhere in the middle, with emphasis being placed upon the weightier Principle of Totality."[12]

Pacholczyk rightly concludes that a woman can surely make a prudential judgment that she carries a serious risk of breast cancer due to BRCA1/2 mutations, as well as considering other factors such as a strong family history of breast cancer, the absence of a full-term pregnancy, abortion or miscarriage in the first pregnancy, or a male relative who develops breast cancer.[13]

Salpingectomy is prudential management medical treatment and morally permissible surgery.

[1] Consult: Rachelle Barina, "Risk-Reducing Salpingectomy and Ovarian Cancer," *The National Catholic Bioethics Quarterly* 14:1 (2014), 67-79 and John F. Tuohey, "Surgical Prophylactics for Ovarian Cancer (SPOC): An Ethical Inquiry," *Linacre Quarterly* 65:3 (1998), 77-96.
[2] Jolie's mother and aunt both died of breast cancer. She chose this surgery as her risk of breast cancer was higher than her risk for ovarian cancer.
[3] http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA
[4] Gynecologic Oncology Statement Regarding Salpingectomy and Ovarian Cancer Prevention, November 2013, https://www.sgo.org/linical-practice/guidelines/sgo-climnical-practice-statement-salpingectomy-for-ovarian-cancer-prevention/.
[5] NCCB, *Ethical and Religious Directives for Catholic Health Care Services* (ERDs), 2009, no. 53.
[6] John Paul II, *Veritatis Splendor* (1993), no. 80. See also Thomas Aquinas, *Summa Theologiae* I-II, q. 65, a. 1.
[7] ERDs, *op. cit.,* no. 53.
[8] Barina, *op. cit.*, 72, referencing "Removal of a Healthy Organ" in *The Human Body,* Boston: Daughters of St. Paul, 1960, 277-279.
[9] This same conclusion was reached by Thomas J. O'Donnell, "Definitive Pelvic Surgery: A Moral Evaluation," *Theological Studies* 22:4 (1961), 652-653.
[10] Pope Pius XII, *AAS* 44 (1952), 782.
[11] See Gerald Kelly, S.J., "Pope Pius XII and the Principle of Totality, " *Theological Studies* 16: 2 (1955), 373-396.
[12] Fr. Tad Pacholczyk, "'Drastic Measures' and Cancer Decisions,'" (November 7, 2014), http://ncbcenter.org/page.aspx?pid=1101.
[13] See Victoria Colliver, "UCSF Study To Look at Effects of Premature Change As A Result of Preventive Breast or Ovary Removal," Health. SFChronicle.com and SFGate.com, November 19, 2014.

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The fear and emotional angst many women experience from a heightened risk of developing ovarian cancer can be overwhelming, especially if they have lost family members to this dreaded disease.

Since Catholic health systems carry a moral obligation to care for the whole person, attending to such fears and anxiety is essential when ministering to these patients. The difficult decisions these women and their families face requires our support and the best medical care we can offer. At the same time, Catholic ministries must respond in a way that ensures respect for human dignity and the whole human person, including the gift of fertility.

In light of this background, we consider prophylactic salpingectomy for a patient at increased risk of ovarian cancer. Pope Pius XII acknowledged that the Principle of Totality can justify removing a healthy organ if "its continued presence or functioning cause[s] either directly or indirectly a serious menace for the whole body."[1] Applying this same principle, the *Ethical and Religious Directives for Catholic Health Care Services* (*ERDs*) states that "the functional integrity of the person may be sacrificed to maintain the health or life of the person when no other morally permissible means is available."[2] Both of these sources are clear that the Principle of Totality does *not* apply to direct sterilization.[3] However, we believe that prophylactic salpingectomy for patients at increased risk of ovarian cancer can rightly be characterized as an *indirect* sterilization, per the usual conditions of the Principle of Double Effect and Pius XII's note on the Principle of Totality. Though sterility is foreseeable, it is an unintended secondary effect. Such effect is neither the direct object (proximate intention) of the salpingectomy nor the remote intention of the patient or physician. Rather, its purpose is to reduce the risk of cancer in the face of danger. Finally, the sterilizing effect is not the cause or specific means used to reduce the risk of ovarian cancer.

Although prophylactic salpingectomy meets the first three conditions for double effect, it is more difficult to determine whether the good effect outweighs the bad. Attaining *absolute* certitude that the benefits of prophylactic salpingectomy are greater than the risks is not possible, nor required in the Catholic moral tradition. One need obtain only *moral* certitude, or the certitude of prudence. Burdens to consider in this analysis include the unintended effect of loss of child-bearing potential, the surgical risks, a continued risk of ovarian cancer due to the presence of the ovaries, a possible increase in risk for ectopic pregnancy, and bleeding from this highly vascularized tissue.[4] Moreover, it is uncertain that she would actually ever develop ovarian cancer. This raises the question of whether the danger or risk constitutes a proportionate reason for undergoing the surgery.

The anxiety caused by an increased risk of ovarian cancer could limit a person's moral resources. For example, a young mother might want to do everything within her power to see her children grow up. This psychological and social benefit, grounded in the real possibility she will develop cancer, are indicators of the increased burdens and risks that might justify undergoing the procedure. However, the same fear might motivate someone to request prophylactic surgery when less invasive interventions (e.g.

counseling, screening) may be more appropriate. The personal decision to proceed with prophylactic salpingectomy should occur on a case-by-case basis only after careful conversations between the patient and her physician.

Ultimately, obtaining moral certitude about this case would require detailed information about the patient's medical history, genetic testing, personal history, race and ethnicity, and other clinical risk criteria. Thus, we must assume we have moral certitude that the risk of developing cancer is high enough to outweigh the burdens of surgery and infertility but not the burdens of early menopause, else the ovaries would be removed too.

Further specification of what constitutes a proportionate reason in this case would aid in obtaining moral certitude. This case reveals a need for further consideration on the risk-benefit analysis for women at population risk of ovarian cancer. These considerations are vital for Catholic ministries to continue to uphold the dignity of all women at risk of ovarian cancer.

[1] Pope Pius XII, "Removal of a Healthy Organ" (October 8, 1953), *The Human Body: Papal Teachings*, pp.277-279.
[2] United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services,* 5th ed, no. 29.
[3] In "Removal of a Health Organ," Pope Pius goes on to say, "We would like, however, to draw your attention to an erroneous application of the principle of totality which we have enunciated. It not rarely happens that, either when gynecological complications demand an operation, or quite independently of such complications, the healthy fallopian tubes are removed or put out of action [in order] to prevent any new conception and the grave dangers which could arise therefrom either to the health or life of the mother; these dangers arise from other unhealthy organs—kidneys, heart, lungs—whose condition would be aggravated in case of childbearing…The appeal to this principle here is unjustified…" (*op. cit.*) The *Ethical and Religious Directives* state, "Procedures that induce sterility are permitted when their direct effect is the cure or alleviation of a present and serious pathology and a simpler treatment is not available." (*op. cit.*, n. 53)
[4] The last two risks are not specified in the clinical practice statements recommending prophylactic salpingectomy concurrent with an unrelated abdominal surgery; Society of Gynecologic Oncology, "SGO Clinical Practice Statement: Salpingectomy for Ovarian Cancer Prevention," November 2013. Society of Gynecologic Oncology of Canada, "GOC Statement Regarding Salpingectomy and Ovarian Cancer Prevention," September 2011.

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The moral question of whether risk-reducing salpingectomy (RRS) or risk-reducing salpingo-oopherectomy (RRSO) could be permitted as means of preventing ovarian cancer (OC) is a relatively new one. While *Ethical and Religious Directive* (*ERD*), no. 53 prohibits "direct sterilization" and states that "[p]rocedures that induce sterility are permitted when their direct effect is the cure or alleviation of a present and serious pathology and a simpler treatment is not available[1], it does not address whether a currently non-pathological reproductive organ can be removed if there is evidence that it is likely

to endanger a woman's health or life, but is not (yet) presently and seriously pathological.

Not Illicit "Uterine Isolation"

The citation for ERD 53 suggests its scope. The footnote references sole document, the Congregation for the Doctrine of the Faith's 1993 "Responses on 'Uterine Isolation' and Related Matters," which addressed three questions that are morally distinct from RRS and RRSO: 1) a uterus could be removed if it poses an "immediate serious threat to the life or health of the mother" even though sterility may result; 2) a uterus may not be removed if it does not constitute "in itself a present risk to the life or health of the woman" AND the intention is "to prevent a possible future danger deriving from conception"; and 3) a tubal ligation or "uterine isolation" with the intention of "averting the risks of a possible pregnancy" is not permitted. The latter two are not permitted because "the described procedures do not have a properly therapeutic character but are aimed in themselves at rendering sterile future sexual acts freely chosen.[2] The current case study differs from the latter two scenarios in three ways: 1) a known "immediate serious threat to the life or health of the mother" does not yet exist, though there seems to be some evidence that the woman is at increased risk of experiencing a serious threat to her life or health;[3] and 2) the fallopian tubes themselves may contain the risk; and 3) sterility is not the *means* by which risk to a woman's life would be averted but a *side effect* of a procedure directly aimed at removing potentially life-threatening tissue.

Not "Direct Sterilization"

A "direct sterilization" is an action "whose sole, immediate effect is to render the generative faculty incapable of procreation."[4] In RRS and RRSO for at-risk women carried out with a prophylactic intention, the sterilizing effect is *not* the sole, immediate effect; rather, there is a second concurrent effect of removing organic tissue that, regardless of the occurrence of pregnancy, threatens to endanger a woman's life or health.

Permissibility of Removing a Currently Non-Pathological Organ

That an organ is not currently pathological does not morally exclude its removal.[5] Pope Pius XII invoked the Principle of Totality to justify removing a currently non-pathological organ,[6,7] including in the context of a meeting with urologists concerned about the morality of castration to thwart prostate cancer.[8] The tradition has also justified prophylactic removal of currently non-pathological appendices during other abdominal surgeries.[9]

Key to the application of the Principle of Totality is the existence of a proportionate reason for impairing functional integrity.[10] The greater the impairment, the stronger the reason must be. It would be difficult to make this case for RRS and/or RRSO for women without an increased risk of ovarian cancer; however, it seems plausible in certain cases for at-risk women.

Requirements of the Principle of Double Effect

RRS and RRSO may be justified by the Principle of Double Effect if: 1) the moral object (removing organ[s] that poses a potential serious threat to life or health) is good or at least indifferent; 2) the good effect (reduced threat to life and health) and not the evil effect (sterility) is intended; 3) the good effect (reduced threat to life and health) is not produced by means of the evil effect (sterility); 4) there is a proportionately grave reason for permitting the evil effect.[11] The moral evaluation of RRS in our case study seems to hinge on the "proportionate reason" criteria. Among relevant factors are the life-threatening nature of OC; the difficulty in obtaining a timely diagnosis before the disease has become serious or deadly; the reliability of methods to predict increased risk of OC in light of the woman's genetics, family history, and age; the average age of onset of OC; medical and surgical risks and benefits; the existence or lack of alternatives; the effectiveness of RRS and / or RRSO in reducing the risk of OC; a person's duty as steward to preserve her life and health; her fertility; and her vocational responsibilities (such as that of a mother to care for her existing children). Beyond favorable medical and surgical risk / benefit ratios, there is no mathematical formula to determine whether a morally proportionate reason exists. Such discernment should be carried out on a case-by-case basis, with the most up-to-date medical available, and from the perspectives of the acting persons.

The Guiding Role of Prudence

Prudence may guide the conscience to act to preserve life and health in the face of a reasonable threat; it does not require a person to enter into a cancerous state before acting, particularly if waiting until the time of diagnosis to intervene could be fatal.

In the sacred relationship between physician and patient, the vulnerability of the pregnant woman should be acknowledged in the informed consent process. By nature, pregnancy puts a decision for RRS or RRSO accompanying a C-section on a timer, and caution is needed to avoid pressuring a woman to make this permanent decision before she has had adequate time to form her conscience. As a matter of prudence, she should be allowed sufficient moral space to consider how her current context (e.g. a particularly miserable pregnancy or young active children) may influence her readiness to accept that she will no longer be able to have another child or how a change in her context (e.g., the death of a child, widowhood and remarriage) may cause her to weigh the sterilizing side effect of the intervention differently. These contextual considerations are discerned by the woman herself and therefore should to be brought to light as part of the informed consent process.

A Catholic health care institution could encourage prudential discernment by making available genetic counseling[12] and ethics consultation[13]. To prevent abuse that could arise with an unregulated policy regarding RRS and RRSO, the Catholic

health care institution may consider requiring prospective and/or retrospective case review. To mitigate scandal, it should be prepared to explain the moral distinction between RRS/RRSO and direct sterilization.

[1] United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, D.C: United States Conference of Catholic Bishops, 2009), no. 53.

[2] Congregation for the Doctrine of the Faith, "Responses on 'Uterine Isolation' and Related Matters," *AAS* 86 (1994): 820-821.

[3] The case study itself does not indicate the risk in this particular woman in light of her reported family history. Here, the ethicist relies on medical judgment.

[4] Congregation of the Doctrine of the Faith, "Responses to Questions Concerning *Quaecumque Sterilizatio*" *AAS* 68 (1976): 738-740, no. 1.

[5] Thomas O'Donnell, S.J., "Definitive Pelvic Surgery: A Moral Evaluation," *Theological Studies* 22, no.4 (December 1961): 652-653: "[W]ith regard to the removal of non-pathological tissue, there was a fairly widespread opinion in the past (based perhaps on a misinterpretation of St. Thomas' treatment of mutilation) which demanded that an organ be diseased before its removal was justified. This is incorrect. It is a distinction not even mentioned by many of the standard moral theologians, and expressly denied by others, and is clearly incompatible with the following statement of Pope Pius XII in his address to the Twenty-seventh Annual Convention of Italian Society of Urologists."

[6] Pope Pius XII, "Address to the First International Congress on the Histopathology of the Nervous System," (September 14, 1952): "Because [the person] is a user and not a proprietor, he does not have unlimited power to destroy or mutilate his body and its functions. Nevertheless, by virtue of the principle of totality, by virtue of his right to use the services of his organism as a whole, the patient can allow individual parts to be destroyed or mutilated when and to the extent necessary for the good of his being as a whole. He may do so to ensure his being's existence and to avoid or, naturally, to repair serious and lasting damage which cannot otherwise be avoided or repaired." English translation available at http://ncbcenter.org/page.aspx?pid=1238 . Here the words "ensure" and "to avoid" seem to suggest a prophylactic intervention.

[7] Pope Pius XII, "Address the Twenty-sixth Congress of the Italian Association of Urologists," *AAS* 45 (1953): 674–675: "Three conditions govern the moral licitness of surgical intervention which entails anatomical or functional mutilation. First, the continued presence or functioning of a particular organ causes serious damage to the whole organism or constitutes a threat to it. Secondly, the harm cannot be avoided or notably reduced except by the mutilation which, on its part, gives promise of being effective. Finally, one can reasonably expect that the negative effect—i.e., the mutilation and its consequences —will be offset by the positive effect: removal of danger to the entire organism, palliation of pain, etc. The decisive point here is not that the organ which is removed or rendered inoperative be itself diseased, but that its preservation or its functioning entails directly or indirectly a serious threat to the whole body. It is quite possible that, by its normal function, a healthy organ may exercise on a diseased one so harmful an effect as to aggravate the disease and its repercussions on the whole body. It can also happen that the removal of a healthy organ and the suppression of its normal function may remove from a disease—cancer, for example—its area for development or, in any case, essentially alter its conditions of existence. If no other remedy is available, surgical intervention is permissible in both cases."

[8] See ibid.

[9] See Thomas J. O'Donnell, S.J., *Morals in Medicine*, (Westminster, MD: Newman Press, 1959), pp. 85-86.

[10] See ERD 29, and Gerald Kelly, S.J., "Medical-Moral Problems," (St. Louis: The Catholic Health Association of the United States and Canada,1958), p. 36: "Since mutilations vary in degree, the reasons justifying them must also vary. The cure of a slight danger may justify a slight mutilation, whereas the removal of an important part or the suppression of an important function requires a very serious reason."

[11] Joseph Mangan, "An Historical Analysis of the Principle of Double Effect," *Theological Studies*, 10 (February 1949): 43.
[12] See *ERD* 54.
[13] See *ERD* 37.

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When this patient undergoes risk-reducing salpingectomy (RRS), the nature and purpose of the act is disease prevention. Although RRS will render her incapable of procreation, inducing sterility is not the purpose of the procedure or the intention of the patient in the case at hand. Consequently, I believe RRS constitutes a permissible, indirect sterilization for this high-risk patient.[1] Although a more thorough and systematic ethical reflection on the act of RRS is appropriate, I would like to focus this commentary on two long-term ethical considerations that become especially relevant if Catholic health care organizations are willing to perform RRS: 1) offering and/or recommending RRS, and 2) the meaning of pathology and other related concepts.

In the present case, this highly informed patient asks about RRS, which obscures the question of whether clinicians should offer or recommend RRS. Many patients with higher than average risk will not know about RRS. Moreover, people (including physicians) tend to understand and appreciate risk very poorly.[2] Concern about the potential risks of RRS persists, and definitive data on its efficacy does not exist.[3]

Because these factors increase women's vulnerability, it is crucial to remember the implicit power that physicians hold. When a physician presents an option, many patients hear that option as a recommendation. While RRS may be morally permissible, I am concerned about expectations generated from physicians' support of risk-reducing procedures. Undertaking preventative care is generally seen as responsible patient behavior. While RRS obviously differs from routine preventative care, physician recommendations could contribute to a perception that RRS is the responsible reaction to evidence of inherited risk. The belief that undergoing a preventative procedure is a responsible act generates a subtle and implicit suggestion that most patients *should* undertake it. Although this sentiment is hard to control when physicians offer or recommend a procedure, it subtly pressures women into accepting an invasive surgery that is morally and clinically optional. In fact, evidence has already shown that many women feel a responsibility not only for knowing and sharing their genetic risk, but also undertaking actions to reduce their risk caused by inherited factors.[4]

Thus, conversations about how and when to counsel women about RRS are necessary. A population health approach to RRS might attempt to quantify and target patients for RRS. Considering Catholic teaching on bodily integrity and the possibility of generating a sense of preventative responsibility for inherited

risk, we should be wary of linking risk-reducing procedures and population health. Instead, Catholic health care organizations should enable conversation not only about if, when, and how to prudently and selectively discuss RRS, but also about how to prevent the spread of an implicit moral imperative that women at high-risk of ovarian cancer undergo RRS.

The case at hand also raises questions about the meaning of pathology. Per ERD 53, procedures that result in sterilization are allowable if their "direct effect is the cure or alleviation of a present and serious pathology and a simpler treatment is not available."[5] This directive was likely written without considering the difference between a harmful malignancy and high risk of malignancy. Should intrinsic risk and the possibility that a malignancy already exists be considered a pathology? Or, given new scientific information, should this language be revised? Austriaco argues that a genetic mutation is sufficient to consider reproductive parts "already diseased."[6] Performing RRS under the assumption that intrinsic risk is disease and/or pathology has far-reaching implications, including theological implications about human nature and embodiment. Even if we are confident that RRS is a permissible, indirect sterilization, we should think carefully before claiming RRS fits within the language of ERD 53. In dialogue with scientific perspectives, new theological scholarship needs to explore the differences between risk, disease, pathology, malignancy, and mutation.[7] Personal, ecclesial, and organizational decisions about invasive responses to hereditary risks depend upon these concepts and will profoundly influence our anthropology and ontology.

While many people might support a RRS for the patient under consideration, clinicians, ethicists, and organizations need to be cautious when approaching RRS on a wider-scale. The way that we approach RRS—clinically and conceptually—will have profound implications for our communities and patients.

I would like to thank Paul Scherz and Devan Stahl for helping me to develop my ideas about RRS.

[1] I have previously made a more lengthy argument in favor of permitting risk-reducing salpingectomy. See "Risk-Reducing Salpingectomy and Ovarian Cancer: Chasing Science, Changing Language, and Conserving Moral Content." *The National Catholic Bioethics Quarterly,* 14 (1), Spring 2014.

[2] For example, see research by Gerg Gigerenzer described in *Risk Savvy: How to Make Good Decisions.* Penguin Group, 2014.

[3]Tanner EJ[1], Long KC, Visvanathan K, Fader AN. "Prophylactic salpingectomy in premenopausal women at low risk for ovarian cancer: risk-reducing or risky?" *Fertility and Sterility*. 100(6), 2013.

[4] For example, see Nina Hallowell's article: "Doing the right thing: genetic risk and responsibility." *Sociology of Health & Illness.* 21(5), Sept 1999. Hallowell interviewed 40 women who underwent genetic counseling for hereditary breast/ovarian cancer. She found that the women perceived a sense of responsibility to their family to undergo testing and manage risk, even when risk management practices involved negative side effects. She effectively argues that the construction of genetic risk is a deeply moral issue because of the way it forms the feelings and choices of women.

[5] ERD 53 of the *Ethical and Religious Directives for Catholic Health Care Services*. 5th edition, 2009.

[6] Nicanor Pier Giorgio Austriaco provides a helpful and scientifically adept Catholic moral discussion of risk-reducing procedures that result in sterilization in his book, *Biomedicine and Beatitude: An Introduction to Catholic Bioethics*. Catholic University of America Press, 2011. see pages 219-221. Quote from page 221.

[7] This research should also examine if/how genetic risk factors differ from environmental or behavioral risk factors.

Ethicists in Catholic Health Care: Taking Another Look

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In 2008, CHA conducted a survey of ministry ethicists and a related survey of mission leaders who carry out the ethics function in their organizations. The purpose of the surveys was to obtain initial, baseline information about the ethics role and its multiple dimensions within Catholic health care. In addition to gaining a better understanding of the ethics role, the surveys were designed to obtain data that could be helpful for hiring and recruiting qualified ethicists, standardizing qualifications and competencies, providing educational and development programs, engaging in strategic planning, and planning for the future. Some results of the surveys generated concerns in light of their implications for the future role of ethicists and the future of ethics in Catholic health care. CHA responded to these concerns through a variety of initiatives including development of desired competencies and qualifications for ethicists in the ministry, fostering relationships with graduate students in ethics, and developing a hybrid online and in-person course for mission leaders who carry on the ethics function or are responsible for ethics in their organizations.

In early 2014, CHA conducted a follow up survey focusing on ministry ethicists associated with a system or facility. Eighty-one ethicists received the survey and forty-seven completed all or a portion of it for an overall response rate of 73 percent. Although everyone did not answer every question, generally there was a sufficient response to the questions to yield useful information. What follows is a summary of the survey divided into the same four parts as the original survey:

- Who are ministry ethicists?
- What do ministry ethicists do and think about?
- Perceptions of ethics within organizations.
- Looking to the future.

When relevant, comparisons are made with the results of the 2008 survey.

Who Are Ministry Ethicists?

Gender, Age, Religious Affiliation, and Educational Preparation

As with the earlier survey, the majority of professional ethicists in Catholic health care are male (62 percent), Caucasian (97 percent), lay (81 percent), and Roman Catholic (86 percent). The majority, 63.6 percent, hold a Ph.D. or the equivalent. Of those with a Ph.D. who responded, slightly more hold a degree in health care ethics or philosophy than hold a degree in moral theology or theology. These numbers have not changed significantly from the previous survey, although the

percentage of males and those holding Ph.D.s is slightly down, whereas the percentages of lay and Roman Catholic ethicists have increased by 3 percent and 8 percent respectively.

Location

As noted in the 2008 survey, the "location" of professional ethicists in Catholic health care has important implications for desired qualifications and competencies of future ethicists. Survey results show that 20.6 percent of the ethicists who responded are employed by a national health care system, whereas 52 percent indicated that they are employed by a regional system, and 11 percent by an acute care facility.

Age, Experience, Longevity in the Role and a Succession Plan

As with the earlier survey, the age of ethicists in Catholic health care is of some concern. The largest percentage, 36.4 percent, is between ages 60-69. This is slightly higher than the previous survey that found 31.1 percent at 60 and above. The second and third largest age cohorts are 50-59 (25 percent) and 30-39 (18.2 percent) respectively. The three smallest age groups are 40-49 (13.6 percent), 20-29 (4.5 percent) and 70+ (2.3 percent). This means that approximately 63.7 percent of ethicists in Catholic health care are between the ages of 50-70+, while 36.3 percent are between the ages of 20 and 49.

One survey question asked about years of experience as an ethicist. Those who indicated that they had 6-15 years represented 38.2 percent, while 32.4 percent noted 16-29 years. The lowest numbers were at either end of the spectrum: 8.8 percent indicated 30 or more years, while 20.6 percent indicated 1-5 years.

When asked how many more years they planned to work as an ethicist, 29.4 percent responded 1-5 years. On the other hand, 41.2 percent said they planned on working as an ethicist 6-15 more years, 8.8 percent plan on 16-29 more years and 20.6 percent plan on working 30 or more years. This suggests that within five years, almost 30 percent of ethicists currently in Catholic health care will no longer be in that role. This is fairly significant for the future of the ethics role. On the other hand, almost 30 percent say they plan on remaining in the role for another 16-30 years. The largest group, 41.2 percent, plans on continuing for 6-15 years. Hence, within 15 years, Catholic health care could lose 70.6 percent of its ethicists.

Only 31.4 percent indicated that their organization has a succession plan for their position.

What was said about age in the 2008 survey applies today, especially when coupled with responses to the new question about expected length of time remaining in the role. "These numbers not only suggest an aging cohort of professional ethicists, but also, of even greater concern, disproportionately fewer ethicists coming into Catholic health care than those approaching retirement age. Absent some fairly aggressive measures, we

are facing a shortage. Leaving these positions vacant or filling them with individuals who might not have the desired qualifications, competencies and experience could eventually have a negative impact on ethics in Catholic health care at a time when the issues are becoming increasingly complex" (Hamel, "A Critical Juncture," *Health Progress* 90, no. 2 [March-April 2009], p. 15).

Title and Reporting Relationships

Because titles may indicate the degree to which a particular role is valued by an organization, the survey asked about position titles of professional ethicists and the titles of those to whom they report. The majority of ethicists responding hold the title of Director of Ethics (33.3 percent), whereas 3.0 percent are Senior Directors, 9 percent are VPs of Ethics, and 6.1 percent are Senior VPs of Ethics. 6.1 percent hold the title of Ethicist. 42.2 percent indicated "Other." At least some of these are likely to be titles combining mission and ethics.

As might be expected, the majority of ethicists in an acute care setting hold the title of ethicist (20 percent) or director of ethics (80 percent). But surprisingly, 33 percent of ethicists at regional systems and 29 percent at national systems have the title of director of ethics. Only 6 percent of ethicists at a national or regional system have the title of vice president, ethics or senior vice president, ethics. Twenty-nine percent of ethicists at a national health care system hold the title of vice president, ethics and 14 percent have the title of senior vice president, ethics. It should be noted here, however, that other titles might also be at play. Fifty percent of respondents who are located in a regional system and 29 percent of those in a national system indicated "Other" for their title. Some of these have a variation on the ethics title (e.g., director, clinical ethics, executive director, ethics), while others combine mission and ethics in their title (e.g., vice president, mission and ethics; vice president mission services).

As might be expected, most ethicists report to a mission leader (58.8 percent). Those who report to someone with the title of senior vice president of mission represent 35.3 percent, while 23.5 percent report to a vice president of mission. Twenty percent report directly to the CEO.

At minimum, these results raise the question of whether the ethicist should be equal in title and status to the mission leader. This is especially true when one considers that the majority of ethicists hold a Ph.D. and deal with extremely complex and grave issues.

Compensation

CHA staff often receives inquiries about the range of compensation for professional ethicists in Catholic health care. Needless to say, compensation varies considerably depending on the size of the health care organization, whether it is a system or facility, region of the country in which it is located, professional degree, title, experience and responsibilities. The survey found that salaries ranged from about $50,000 to over $450,000.

- 8.8 percent earn between $50,000 and $75,000
- 20.6 percent earn between $75,001 and $100,000
- 14.7 percent earn between 100,001 and $125,000
- 8.8 percent earn between $125,001 and $150,000
- 8.8 percent earn between $150,001 and $175,000
- 8.8 percent earn between $175,001 and $200,000
- 11.8 percent earn between $200,001 and $225,000
- 5.9 percent earn between $225,001 and $250,000
- 2.9 percent earn between $250,001 and $275,000
- 2.9 percent earn between $300,001 and $325,000
- 2.9 percent earn between $425,001 and $450,000
- 2.9 percent earn $450,000 and above.

Approximately 60 percent of ethicists working in an acute care facility earn between $75, 001 and $100,000 and approximately 20 percent earn between $100,001 and $125,000 and another 20 percent between $150,001 and $175,000. Regional ethicists' salaries range from between $50,000 and $75,000 all the way to between $300,001 and $325,000. The majority lie between $75,001 and $150,000. Approximately 30 percent of ethicists at a national health care system earn in the $100,001 to $125,000 range with the remainder fairly evenly distributed in the other salary ranges up to $450,000 and above.

Ethicists with the title of "ethicist" earn between $50,000 and $100,000. Those with the director of ethics title fall into virtually every category above with the majority in the $75,000 to $100,000 category (approximately 37 percent), followed by approximately 28 percent in the $100,001 to $125,000 range and about 12 percent in the $125,001 to $150,000 range. Several of the higher ranges contain only about 6 percent each.

Vice presidents of ethics fall between the $125,001 to $150,000 range at the low end and the $250,001 to $275,000 at the high end, with the majority (about 56 percent) falling between $150,001 and $225,000.

Salaries for senior vice presidents of ethics range from $175,000 to above $450,000. About 75 percent earn between $175,000 and $225,000.

What Do Ministry Ethicists Do and Think About?

Roles and Responsibilities

To obtain a better picture of how professional ethicists in Catholic health care spend their time, the survey presented a list to indicate their primary roles and responsibilities. Not surprisingly, the roles and responsibilities that rose to the top were education (97.1 percent), clinical consultations and policy development at 94.1 percent, followed by advising leadership on organizational issues (88.2

percent), development of educational resources (88.2 percent), and working with ethics committees (85.3 percent). Research and writing for publication were the lowest at (52.9 percent) and (44.1 percent) respectively. The differences from the 2008 survey results are relatively minor. The most significant difference is that in the 2008 survey, working with ethics committees ranked second, whereas in the most recent survey, it came in much lower. This could be an interesting finding.

With the exception of leadership development and advising leadership on organizational issues, there was not much difference in the roles and responsibilities among ethicists at a national system office, a regional system office or an acute care responsibility. In all probability, however, while little difference exists in stated roles and responsibilities, differences occur among the three groups in the manner and degree in which those roles and responsibilities are carried out on a daily basis.

A majority of ethicists (57.1 percent) said that their role had changed over the past five years. This was often due to a change in title, a change in location (e.g., from an acute care setting to a regional position) or an explicit broadening of responsibilities under the same title. Changed responsibilities included more church relations, executive formation, analysis of new affiliations and partnerships, mission due diligence, organizational ethics issues, advance care planning, and ethics integration throughout the organization. Most of the role changes occurred with ethicists at a national system.

When asked whether they were a member of the senior leadership team, 31.3 percent of respondents said that they are a member of the senior leadership team, up from 21.4 percent in the previous survey. While this is an improvement, it still means that 68.7 percent of ethicists are not on the senior leadership team. This finding would seem to suggest something about the status of ethicists within their organizations. Similarly, 31.2 percent indicated that they are very or considerably involved in major decision making such as budgeting, planning, joint ventures, etc., while 40.6 percent of respondents said that they are not at all involved.

However, as noted in the earlier survey, "this should not necessarily be construed to mean that ethicists have little influence on senior leadership. What it does mean is that senior leadership may need to examine the degree to which ethics is valued in the organization, as well as how ethics is brought to bear on all dimensions of organizational life, including those areas of the organization represented by senior leadership. What is important is that ethics is brought to bear, and not so much how it is brought to bear. Some clarity about how the ethicist exerts influence is critical to the success of the role. Those ethicists who do not sit at the senior table might do well to examine how they exert influence on the organization as a whole as well as on senior leadership. Is it by participating in discussions on an ad hoc basis, through face-to-face conversations

with senior leaders, or through the mission leader or another person to whom the ethicist reports" (Hamel, *Health Progress* 90, no. 2 [March-April 2009]"A Critical Juncture," p. 17).

Daily Activities

As with the 2008 survey, the activity that most occupied ethicists' time, and this is not surprising, is education (61.8 percent). Clinical consultations and working with ethics committees ranked next at 44.1 percent and 38.2 percent. Research came in at 5.9 percent and writing for publication came in at 2.9 percent.

When asked what they found most satisfying about their work, 44 percent said it was ethics consultations and helping others to resolve difficult ethical issues whether at the clinical or organizational levels. Twenty-seven percent said it was education, particularly of clinical and facility staff, but several also included management and executive leadership. Several mentioned graduate medical education. And 17 percent mentioned helping to shape the culture of the organization, strategy, and systemic change.

The greatest challenge ethicists indicated they face in their organization is being valued by leadership and the ability to influence (45 percent). Some noted that they are called upon at the last minute or are seen as an option of last resort. Twenty-seven percent indicated a range of characteristics associated with their position such as being alone, balancing multiple commitments/responsibilities, fragmentation of role and responsibilities, being spread too thin and not having sufficient time to fulfill responsibilities. Eighteen percent mentioned keeping up with changes in the health care environment.

Issues Occupying Attention

What three issues were most pressing for ethicists over the three months prior to the survey? Most frequently mentioned were ethical issues involved in partnerships, especially with other-than-Catholic organizations. Next were reproductive issues and balancing good patient care with the ERDs. The ACA and challenges around new models of health care delivery resulting from the ACA were next. Other issues mentioned several times each were advance care planning including POLST, contraception and the HHS mandate, and end-of-life care including futile treatment.

Professional Development

When it comes to professional development, a majority of respondents (80.6 percent) said that they attend 1-3 conferences per year, whereas 16.1 percent attend 4-6 conferences per year. These conferences include the CHA Colloquium (87.1 percent), followed by ASBH (the American Society for Bioethics and Humanities, 61.3 percent), the CHA Assembly (45.2 percent), and other programs (38.7 percent). Those who attend the annual meeting of the Society of Christian Ethics represent 25.8 percent and 16.1 percent attend the annual

meeting of the Catholic Theological Society of America.

Professional publications most often read by ethicists responding to the survey were *Health Care Ethics USA,* the *National Catholic Bioethics Quarterly*, the *Hastings Center Report* and *Health Progress.* Distant seconds were *HEC Forum*, the *American Journal of Bioethics*, the *Journal of Clinical Ethics*, *Ethics and Medics*, *Theological Studies* and *Christian Bioethics*. JAMA and the *New England Journal of Medicine* received occasional mention. Most frequently used websites are those for CHA, NCBC, ASBH, Bioethics.net, and Ascension Health.

Contributions of Ethics

When asked what they saw as the most important contribution that ethics makes to their organization, the largest number of respondents noted something along the lines of improving the quality of decisions—clinical and organizational—across the organization. This was followed closely by contributing to the culture of the organization—in particular, creating and sustaining an integrative ethics culture, nurturing organizational conscience, and strengthening mission and Catholic identity. An almost equal number singled out assisting patients, families, and health care providers with difficult decisions.

When looking to the future and how ethics might contribute most to their organization in the next 3-5 years, most respondents to this question said providing ethical input into the development of new delivery systems of care, providing a moral foundation for population health, and providing new ways of offering ethics services in new models of care. Next most frequently mentioned were nurturing a strong ethics culture and ongoing ethics education to empower various individuals and groups (including medical residents and nurses) to better recognize and address ethical issues. These were followed closely by leadership development and formation, being an ethics voice at the organizational table and developing and/or hard wiring a decision-making process for the entire organization.

Moving beyond their organization, ethicists were asked how ethics might contribute to the ministry in the next 3-5 years. Here the largest number of respondents said finding ways to integrate ethics across the continuum of care and re-thinking our ethical frameworks in light of the shift in emphasis beyond the acute care setting. Also frequently mentioned were strengthening Catholic identity and ethics education, including the development of tools and apps for clinicians and organizational leaders. These survey results may well suggest a need of ongoing education of ethicists in Catholic health care to better address the changing health care environment and to better meet the challenges that it poses. They may also have implications for the preparation of new ethicists.

Looking to the Future: The Next Generation of Ethicists

Survey questions related to the future of the profession dealt primarily with educational preparation for future ethicists, desired experience, and suggestions for recruiting future ethicists for Catholic health care.

Desired Core Competencies

What two or three core competencies will future ethicists need in order to be effective for the ministry? The most frequently mentioned response centered on theological competency, including knowledge of the Catholic moral tradition, Catholic social teaching, and ecclesiology. Next came clinical experience, communication skills, knowledge of the health care system, including an ability to communicate with providers and awareness of organizational ethics issues. Finally, several respondents mentioned the ability to conduct clinical consultations. These results closely parallel those in the 2008 survey.

Needed Experience

When asked what experience future ethicists will need in order to be effective in the ministry, respondents most frequently cited clinical experience and previous work in a health care setting. Very close seconds were familiarity with the fundamentals of business and strategy, operations, and how to interface with senior leaders. Clinical/hospital/health care experience was also cited by slightly more than half of the respondents in the previous survey. These findings may be helpful not only in developing position descriptions, but also in preparing future ethicists for a career in the ministry.

Essential and Desired Educational Preparation

Asked about essential educational preparation for someone doing health care ethics in the future, 70.4 percent of respondents said that a master's degree is essential, while 29.6 percent said a Ph.D. is essential. This is different from the earlier survey when 51.3 percent said a Ph.D. was essential and 35.9 percent said a master's degree was essential. However, 75.9 percent said that a Ph.D. would be desirable. These results probably merit further discussion. Is a master's degree sufficient, especially if the ethicist is interacting closely with physicians or holds a system position? What impact if any might this have on how the ethics position is viewed by administration?

Recruiting Future Ethicists

Respondents offered several suggestions for attracting new ethicists into Catholic health care. One was to connect with high schools and universities (graduate and undergraduate) to help students become aware of possible careers in Catholic health care. Related to this was offering work-study programs, internships and fellowships to those students who may have an interest, and continuing to foster student participation in CHA activities together with scholarships to the annual Colloquium and the student essay contest and, possibly, student colloquia. The other most frequently mentioned

suggestion was reaching out to health care professionals who might have an interest in ethics and who might consider professional training in ethics to accompany their current careers or who might consider a second career in Catholic health care ethics. In conjunction with this, a few also suggested a mentoring program for such individuals and developing an ethics career track or training program for them.

Concluding Observations

Readers will have their own interpretations and observations regarding the results of CHA's 2014 Ethicist Survey, but a few preliminary observations are offered here. Hopefully, these results will serve as a basis for ongoing discussions and will contribute to planning, programing, hiring and the like across the ministry.

1. **Catholic health care continues to have an aging cohort of professional ethicists.** While there are new and younger ethicists in the pipeline, it seems unlikely that there will be sufficient numbers to replace ethicists retiring in the next five to ten years. If this challenge is going to be met successfully, it would seem that all of Catholic health needs to redouble its efforts to make students at various educational levels aware of a possible career as a Catholic health care ethicist, develop and implement ways to nourish and support potential candidates, and perhaps look to existing health care professionals who might be interested in a second career or at least a concentration in Catholic health care ethics.

2. **There is a lack of diversity among Catholic health care ethicists.** As the survey results indicate, the majority of ethicists in Catholic health care are male and Caucasian. In the effort to recruit new ethicists, it would behoove Catholic health care to make deliberate efforts to attract and, perhaps, even identify and nurture, individuals who would bring gender and racial diversity.

3. **There is a shift in the educational backgrounds of newer ethicists.** The majority of older ethicists in Catholic health care were and are theologians. Their degrees, Ph.D.s or STDs, are in theology, mostly because they are clergy, former clergy, members of religious communities, or seminary trained. This is generally not true of newer ethicists who tend to be obtaining their degrees in health care ethics, a more multidisciplinary approach (which has its own strengths). While most of these programs do incorporate some theology in their curricula, it does not result in the theological breadth and depth of previous generations of ethicists. It may be that newer ethicists in Catholic health care need not be theologians in order to serve the ministry well, but they certainly need to be well-versed in the Catholic moral tradition at least, in order to adequately meet the challenges of a faith-based ministry of the Church, as

a good number of respondents noted in the survey.

4. **The responsibilities of ethicists seem to be changing with rapid changes in the health care delivery system.** In many of the responses, there are early indications of a shift in the responsibilities of ethicists both in the acute care setting and at national and regional system levels. All three tend to be dealing with the extension of ethics services throughout the continuum of care. This will likely require knowledge of differing cultures across the continuum, new ways of delivering services, and some new skills. With the explosive growth in new affiliations and partnerships, system ethicists will likely be more involved in addressing ethical dimensions of these relationships, some of which will involve complex applications of the Principle of Cooperation (and, possibly, toleration). These developments have implications for the adequate preparation of new ethicists.

5. **As in 2008, survey results raise some questions about how well the ethics role is valued and integrated within Catholic health care organizations.** Are ethics and the ethics role viewed as integral to the life of the organization or are they seen as nice to have around when crises develop or other difficult problems arise? How is the ethics role positioned within the organization and how is it used? Survey results suggest that administrators and ethicists themselves would do well to reflect on the place of ethics and the ethics role within their organizations. Ethics is at the heart of mission. If ethics is seen as an optional add-on or is somehow marginalized, then something essential to mission is missing or diminished within the organization.

6. **Research and publication continue to rank low.** What is not clear in the survey results is why research and publication rank low. Is it because they are not being done or not being done much or because less time is devoted to them than to other responsibilities? If the former, this would be unfortunate and needs to be addressed. No one is better positioned to contribute to the field of Catholic health care ethics than ethicists within Catholic health care. These ethicists are not only part of their particular organizations, they are also part of a much larger whole—Catholic health care. The entire ministry, colleagues across the ministry, and numerous individuals beyond the ministry would benefit immensely from ministry ethicists bringing the Catholic moral tradition to bear on ethical issues that they encounter in their work.

These observations and the survey results themselves are intended to stimulate conversations across the ministry about how we understand, organize, and do ethics and how we ensure a strong and well-prepared cadre of ethicists for the future. Hopefully, such conversations will lead to taking concrete steps to enhance

ethics and the ethics role within the Catholic health care ministry.

More on End-of-Life

In the fall issue of *Health Care Ethics USA,* Ethical Currents began with the observation that "care at the end of life has been receiving considerable attention of late, much of it in the popular press…." Much the same can be said three months later. End of life issues have been very prominent in a variety of media outlets. But whereas the previous attention dealt mostly with improving end-of-life care through better advance care planning and the like, more recent developments raise ethical concerns.

Of course, there were all the media reports about the self-inflicted death on November 1, 2014 of Brittany Maynard, a 29-year-old woman who had terminal brain cancer. At least two major themes emerged from this event. First, as ethicist Arthur Caplan observed, Maynard's youth changed the optics of the debate over physician-assisted suicide. Two videos she created for Compassion and Choices, posted on You Tube, generated more than 15 million views as of mid-January 2015. Maynard was featured on the cover of *People* magazine, appeared on several network morning and evening news programs and posted a page on the Compassion and Choices website that attracted more than five million visits. Compassion and Choices chief program officer noted that "nothing has touched as many people as Brittany's story and changed the dialogue around death with dignity the way this has." (Paula Span, "A New Face on the End-of-Life Debate," *New York Times*, November 5, 2014). This may well be the case.

Second, Compassion and Choices President Barbara Combs Lee stated that there is no more fundamental right than the right of the terminally ill to control the manner and timing of their death. This belief was a constant refrain before and after Brittany Maynard's death and it seems to be gaining popularity judging by the frequency with which it was appealed to by so many who commented on Maynard's death. A survey of more than 21,000 physicians conducted by Medscape from September through November 2014 and published in December 2014 found that 54 percent of physicians supported the right of patients with an incurable illness to seek "a dignified death" (Medscape Ethics Report 2014 at http://www.medscape.com/features/slideshow/public/ethics2014-part1?src=ban_wnl_2). This was up from 46 percent when the same question was asked in a 2010 Medscape survey.

In a December 26, 2014 op-ed in the *LA Times*, a journalist and retired family medicine physician wrote: "Clearly, we can no longer hide behind the flimsy shield of the Hippocratic oath. The drumbeat for change has begun. To pretend otherwise shows a lack of compassion and a disregard for not just for medicine but for the dignity of life." They go on to say: "But perhaps we should set aside the debate over the [Hippocratic] oath and what it means. Should we allow our dedication to an ideal … to outweigh an individual's stated

choice of forgoing pain and suffering? If we allow medicine to prolong life, should we also allow it to shorten life for the terminally ill?" So as not to burden physicians who oppose aid-in-dying, the authors suggest forming a new class of medical professional—licensed death doulas—who would oversee the end of life for the terminally ill (Nora Zamichow and Ken Murray, "The Hippocratic Oath and the Terminally Ill").

A Pew Research poll in 2013 found that 63 percent believed that a person has a "moral right" to suicide when "suffering great pain with no hope of improvement" (up from 55 percent in 1990), though 49 percent say they oppose doctor-assisted suicide for the terminally ill (http://www.pewresearch.org/fact-tank/2014/10/22/americans-of-all-ages-divided-over-doctor-assisted-suicide-laws/).

A seeming shift in public sentiment regarding the legitimacy and availability of physician aid in dying is evidenced in the growing number of state legislatures that are considering its legalization. Oregon, Vermont and Washington are currently the only three states with aid-in-dying legislation in place. New Mexico and Montana have court rulings that protect physicians who help patients to die.

Currently, there is aid-in-dying activity in at least six states. In California, Compassion and Choices has hired staff, held community meetings, and is lobbying local public officials. On January 22, 2015, two California state senators introduced a bill that would legalize physician aid-in-dying. A recent poll there found that nearly two-thirds of those asked would vote in favor of such a bill. Two state legislators in Colorado are drafting legislation modeled after the Oregon law that they hope to introduce this year. This follows on the heels of a very public request to legislators last year by an ALS patient explicitly asking them in an open letter in the *Denver Post* to "show mercy on the terminally ill. Please." Charles Selsberg, the 77-year-old who died because he stopped eating, has become the face of proposed legislation in Colorado.

In New Jersey, the State Assembly passed a bill in late 2014 and a senate committee voted toward the end of December 2014 to allow the New Jersey Death with Dignity Act to proceed to the full senate for a vote. A state senator from Manhattan is seeking support for a bill that is modeled after the Oregon law. While unlikely to pass in 2015, it has raised the issue among New Yorkers. In Pennsylvania, two legislators entered bills into the state house and senate last year, bills that are also modeled after the Oregon Death with Dignity Act. The bills did not come up for a vote before the session ended in December but are likely to be re-introduced in 2015. Finally, there is activity to legalize assisted suicide in Wyoming and Washington, D.C.

Aid-in-dying is taken a step further in a letter to the editor in the November 15, 2014 issue of the *New York Times* (the Sunday Dialogue). The author writes: "Perhaps the moment is right for broaching the idea of what we might call

prophylactic suicide: the decision of an elderly person to pre-empt the grim reaper and avoid the disabilities of extended life. … [A] recognized right to assisted suicide for those over 80 would ensure a painless death and allow an elderly person's loved ones to be there at the end. As someone who is 85, I know I would appreciate having that choice." (Joyce Appleby, "Prophylactic Suicide, "at http://www.nytimes.com/2014/11/16/opinion/sunday/prophylactic-suicide.html?_r=0).

The legalization of aid-in-dying is not the only end-of-life option being discussed in the popular and professional literature of late. In the January 20, 2015 issue of the *New York Times*, there appeared an article titled "Complexities of Choosing an End Game for Dementia" (http://www.nytimes.com/2015/01/20/health/complexities-of-choosing-an-end-game-for-dementia.html). The author, Paula Span, tells the story of an elderly gentleman who in his advance directive specifies that if he develops Alzheimer's disease or another form of dementia, he does not want ordinary means of nutrition and hydration, generally referred to as voluntarily stopping eating and drinking (VSED).

In November 2014, the *Daily Beast* published an article titled, "The Nurse Coaching People Through Death by Starvation" (by Nick Tabor, at http://www.thedailybeast.com/articles/2014/11/17/the-nurse-coaching-people-through-suicide-by-starvation.html). Judith Schwarz, a 70-year-old nurse who until recently worked for Compassion and Choices, estimates that she has "guided" more than 100 patients through a life-ending fast or VSED. It doesn't require physician assistance, medications, or legal approbation. "According to Schwarz's reasoning, during the late stages of a terminal illness, food can be akin to a life-prolonging drug—especially when the patient has no appetite. Death by pills or lethal injection might be unnatural, but she believes that declining nourishment and medications is not. … She just wants to make it easier for them to act on their choices—particularly if they choose a speedier death."

The Hastings Center Report published two articles in the May-June 2014 issue (Vol. 44, no.3) on withholding food and water by mouth for persons with dementia when they request this in an advance directive. In their article ("Advance Directives, Dementia, and Withholding Food and Water by Mouth," pp. 23-37), Paul Menzel and M. Colette Chandler Cramer argue for a qualified acceptance of this position, while Rebecca Dresser ("Toward a Humane Death with Dementia," pp. 38-40) raises significant concerns about such a practice. A recent article in *The Linacre Quarterly* (vol. 81, no. 3, pp. 279-285) brings the issue home for Catholic health care. Maureen Cavanagh in her piece, "How Should a Catholic Hospice Respond to Patients Who Choose to Voluntarily Stop Eating and Drinking in Order to Hasten Death," examines the ethical issues involved from the perspective of the Catholic tradition and suggests strategies for the Catholic hospice to respond to such requests.

What are some learnings and implications of these "ethical currents" for Catholic health care and the Church? At least two things seem to stand out. First, the tide clearly seems to be changing with regard to societal attitudes toward favoring physician-assisted suicide. It will be extremely difficult if not ultimately impossible to stem this changing tide. In fact, it is probably only a matter of time before we reach a tipping point. The appeal to personal choice and control has great persuasive power in American society and it is very difficult to mount convincing counter-arguments, especially when that choice and control are aimed at ending suffering and a prolonged dying.

Second, the personification of the desire and/or "need" for the right to such choice is powerful and additionally persuasive. Putting a face on situations of actual or probable suffering and prolonged dying seeking relief is also a very effective "argument" and strategy for legalizing physician aid-in-dying. Personal stories, whether in the media or before legislatures, are difficult to counter.

Catholic (and other religious) efforts to prevent or slow the legalization of physician aid-in-dying will need to take account of the personification factor, the appeal to personal choice and control, and will need to offer persuasive reasons why someone's dying should not be hastened when death is inevitable. The challenge here is considerable, especially since much of the recent success in shifting societal attitudes toward physician aid-in-dying is due to an appeal to emotions and not to reason.

Catholic health care in general as well as Catholic health care organizations (systems and facilities) will need to decide whether, to what degree, and how to get involved in opposing legislative efforts. But equally, if not more important, they need to intensify efforts to provide good end of life care both because it is the right thing to do for patients and also so as not to contribute to the problem of unnecessarily prolonged dying processes marked by unrelieved pain and suffering. The Catholic moral tradition provides excellent guidance for providing optimal end of life care. It simply needs to be implemented on a consistent basis in all Catholic health care facilities. And, finally, Catholic health care organizations will need to be clear on their policies and procedures for addressing requests for physician-aid-in dying where it is legal and, now, requests for VSED. Neither of these issues is likely to go away.

RH

Of Note

Rate of Premature Births Fall As Health Law Provisions Begin to Take Effect

According to the annual 2013 March of Dimes report, the number of preterm births is at the lowest percentage in 17 years, 11.4 percent. For the purpose of this report, preterm births were defined as live births that occurred before the pregnancy reached 37 full weeks. Adam Sonfield, a senior public policy associate at the Guttmacher Institute, credits the Affordable Care Act's expansion of insurance coverage with the largest impact on reducing the number of preterm births. Medicaid, which has expanded coverage in 27 states, provides services until 60 days after the woman gives birth, offers consistent coverage pre-pregnancy and provides early prenatal care. Sonfield states that "better access to insurance helps you plan and space your pregnancies, and better access to preventive care helps make sure you're healthy." Michelle Andrews, Nov. 7, 2014, *Kaiser Health News*

Hospitals Split on Ending Aid to Uninsured Who are Eligible for Obamacare

Since the Affordable Care Act started offering subsidized insurance coverage to Americans, some hospitals are adopting policies to limit discounts and free care. The ACA created new guidelines for financial aid policies that not-for-profit hospitals must comply with in order to keep tax exempt status but did not define who is eligible for financial aid. Trinity Health hospitals adopted a policy that may deny discounted care to patients who qualify for subsidized insurance but "refuse or are unwilling" to buy it. Broward Health in Fort Lauderdale wrote a new policy that patients who were approved for a subsidy but chose not to enroll will not qualify for charity care. Other hospitals are not creating new policies because of problems with the enrollment website in 2014, continued consumer confusion or limited options available on state exchanges. Heather Smith, vice president of eligibility and enrollment services at Tenet Healthcare Corp., does not believe policies should be revised because "there is so much education needed." Melanie Evans, Dec. 8, 2014, *Modern Healthcare*

For Diabetes, Stem Cell Recipe Offers New Hope

Douglas Melton, a developmental biologist and his team at the Harvard Stem Cell Institute, have found a recipe to turn embryonic stem (ES) cells and induced pluripotent stem (iPS) cells into mature pancreatic β cells. This breakthrough could lead to a new treatment for patients with Type 1 diabetes by replacing the pancreatic β cells that are destroyed by the body's immune system with new stem cell grown β cells. Melton admits that the protocol "is reproducible, but it is tedious," but it also produces 200 million β cells in a single 500ml flask. Although a big step towards a

cure for Type 1 diabetes, problems remain. It is likely that the autoimmune response that destroyed the original pancreatic β cells would also destroy the new stem cell derived β cells. The researchers are exploring ways to encapsulate the new β cells and modify the β cells to survive an immune system attack. Gretchen Vogel, Oct. 9, 2014 http://news.sciencemag.org/biology/2014/10/diabetes-stem-cell-recipe-offers-new-hope

Genome Sequencing in Babies to Begin as Part of Study

"We are entering an era where all of medicine is genomic medicine," says Robert C. Green, a geneticist and researcher at Brigham and Women's Hospital in Boston. "In the next five to 10 years, as costs come down and interpretation is more established, it will increasingly be to everyone's advantage to have sequencing information integrated into their care." The National Institutes of Health awarded funding to four projects exploring different aspects of genomic sequencing in ill and healthy newborns. Award recipients include University of North Carolina at Chapel Hill, University of California, San Francisco, Brigham and Women's Hospital together with Boston Children's Hospital and Children's Mercy Hospital. Although whole genome sequencing can help identify genetic mutations associated with disease, problems remain. A doctor may not be able to accurately interpret the results because much of the human genome is still a mystery. Other are concerned that the cost is still too high, at least $1,000. Lastly, there are numerous ethical questions left unanswered. Stephen F. Kingsmore, director of the Center for Pediatric Genomic Medicine at Children's Mercy and a leader of the study, says there is "strong logic and good evidence that in acutely ill babies this makes sense. It is not clear at all it makes sense in a healthy baby." Amy Dockser Marcus, Dec. 29, 2014, *The Wall Street Journal*

Pfizer Bets on Gene Therapy as Technology Comes of Age

In a deal with Spark Therapeutics, a privately owned U.S. biotech firm, Pfizer began development of gene therapy with a focus on treating hemophilia B. Michale Linden, a professor from Kings College London and director of the University College London Gene Therapy Consortium, will lead the project on a two-year secondment. Spark Therapeutics will be responsible for Phase I and II testing. Pfizer will conduct late-stage testing, regulatory approval and commercialization. Head of Pfizer research, Mikael Dolsten sees the potential of gene therapy. "The fundamental understanding of the biology of hereditary rare diseases, coupled with advances in the technology to harness disarmed viruses as gene delivery vehicles, provide a ripe opportunity to investigate the next wave of potential life-changing therapies for patients." Ben Hirschler, Dec. 8, 2014 *Reuters*

No Increase in Risky Sexual Activity with HPV Vaccine

A report in the *Canadian Medical Association Journal* found that vaccination of girls against the human papillomavirus (HPV) did not increase or decrease the likelihood of other sexually transmitted infections or pregnancy. Leah M. Smith, lead author of the study from McGill Univeristy in Montreal, noted that this study was larger than previous studies and focused on actual sexual behavior. "The few other studies on HPV vaccination and sexual behavior have focused on perceptions of changes in sexual behavior following vaccination, rather than actual behavior, or have relied on self-reports of sexual behavior, which are notoriously problematic to study because they are vulnerable to the recall bias, response bias, and social desirability bias." In the U.S., studies have shown that concern about increased risky sexual behavior is not a primary reason parents choose not to vaccination their children against HPV. Common reasons not to vaccinate include financial concerns and lack of parental education about the vaccine. Kathryn Doyle, Dec. 8, 2014, *Reuters*

Drugmakers Look to Push the Boundaries of Old Age

Switzerland's Novartis and Denmark's Novo Nordisk are doing a series of testing to see if existing drugs can be used to manipulate or delay the aging process. Aging is a gradual process so researchers are focusing on specific systems that deteriorate with age. Novartis conducted a pilot study of everolimus, a cancer drug, to measure its effect on immunosenescence, the gradual deterioration of the immune system. The pilot study reported a more than 20 percent increase in immune system response for those taking the drug as compared to the placebo group. Mark Fishman, Novartis's head of research, says the study is part of early-stage research that demonstrates Novartis's focus on finding ways to increase healthy years and reduce sickness and dependency at the end-of-life. Caroline Copley, Nov. 5, 2014, *Reuters*

Does Your Average Scientist Need an Ethicist on Call?

Institutional review boards (IRBs) serve as the primary ethical oversight for human-subject research in the United States. Recently, a new resource for ethical dilemmas has become widely available: ethics consultation services. A recent study found that in 2010 more than 30 academic institutions had set up research ethics consultation services but fewer than half of them received calls from researchers seeking advice. Some researchers do not know the services exist or fear that using the service will cause more administrative burdens. Marion Danis, chief of the bioethics consultation service at the NIH Clinical Center, says that ethics consultants can provide guidance throughout a study and offer non-confrontational advice unlike IRBs. Danis continues, ethics consultants offer

"an open space for talking about research ethics in a way that is not driven by the regulatory environment." Some ethicists disagree with Danis' view of ethics consultations. Susan Kornetsky, director of clinical research compliance at Boston's Children's Hospital in Massachusetts, questions the need for ethics consultations if IRBs are responsible for ethics reviews. Elie Dolgin, Oct. 21, 2014, *Scientific American*

Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, assistant director, supervised the contributions of health law students Jeanne Marie Evans (JD anticipated May 2015) and Marie DeFer (JD anticipated May 2015).

Fifth State Passes Right-to-Die Law but Practical Effect is Unknown

Through a voter referendum with over 80 percent support for the bill, Arizona became the fifth state to pass a right-to-die law. The Arizona measure permits terminally ill patients to obtain investigational drugs and medical devices not yet approved by the Food and Drug Administration (FDA). Opponents cite concerns that the law removes important FDA oversight to ensure the safety of drugs and medical devices, and may cause patients to be less willing to participate in clinical trials. Questions remain about the practical effect of the law because state law does not require insurers to cover experimental treatment; it may conflict with federal statutes and regulations; and, pharmaceutical companies may not make available experimental drugs and medical devices to patients. Steven Ross Johnson, *Modern Healthcare*, "For the Dying, State Laws Offer Hope That Critics Call Hollow", Nov. 5, 2014, http://www.modernhealthcare.com/article/20141105/NEWS/311059922

Supreme Court to Review Another Affordable Care Act Case

The Supreme Court announced on November 7, 2014, that it would review the *King v. Burwell* case, which centered around one of the most fundamental provisions of the Affordable Care Act, tax credits that subsidize health coverage purchased on federal exchanges. Oral arguments will be held in the spring of 2015, and a decision will be made by July. The central legal argument revolves around a provision in the ACA that states that people who obtained coverage through state-run exchanges can get federal subsidies such as tax credits. However, the law does not explicitly state that those signing up on the federal-run exchange also are eligible for these subsidies. Adam Liptak, *New York Times,* "Justices to Hear New Challenge to Health Law", Nov. 7, 2014, http://www.nytimes.com/2014/11/08/us/politics/supreme-court-to-hear-new-challenge-to-health-law.html?&hp&action=click&pgtype=Homepage&module=first-column-region&region=top-news&WT.nav=top-news

What Happens to the ACA after the Mid-Term Elections

The November mid-term elections gave Republican control of both the House and Senate. The immediate future of the Affordable Care Act (ACA) is certain: no major changes. The Republican majority is very unlikely to repeal or significantly change the ACA because of the Senate Democrats' filibuster, the GOP does not have enough numbers to override a presidential veto, and with no replacement plan, the ACA's repeal would leave millions of Americans uninsured. Republicans may choose to push patient-centered, market-based, and less regulatory changes, which may also develop the 2016 presidential Republican candidate's health care agenda. In the long-term, the GOP is looking at replacement options for the ACA, like Senators Burr, Coburn, and Hatch's Patient CARE Act. While in early stages of development, the act promises to cover the same number of insured under the ACA, but at a lower cost with less federal control. James Capretta, *Health Affairs* Blog, "Health Care Policy After The Mid-Term Elections", Nov. 7, 2014, http://healthaffairs.org/blog/2014/11/07/health-care-policy-after-the-mid-term-elections/

Lower Health-Care Enrollment Predicted through Marketplace Exchanges

The U.S. Department of Health and Human Services predicts by the end of 2015, 9 to 9.9 million people will have health insurance through health plans sold through federal and state exchanges established under the Affordable Care Act. This number includes people who purchased insurance last year during the exchanges' first year of operation, and will renew plans during this year's open enrollment period of November 15, 2014 to February 15, 2015. While the enrollment prediction numbers are substantial, the estimate is far below the Congressional Budget Office's prediction that 13 million people would have coverage through exchanges by the end of 2015. Amy Goldstein, *Washington Post*, "Obama Administration Predicts Significantly Lower Health-Care Enrollment," Nov. 10, 2014, http://www.washingtonpost.com/blogs/wonkblog/wp/2014/11/10/obama-administration-predicts-significantly-lower-health-care-enrollment/

FDA To Require Calories for Alcoholic Drinks and More

On November 25, 2014, the Food and Drug Administration issued two rules that require operators of chain restaurants, movie theaters and vending machines to clearly display calorie information for food and drink products. These rules encompass calorie counts for movie theater popcorn, other items at concession stands, vended food, cocktails on a drink menu and more. These rules are additions to the menu-labeling requirements passed

in March 2010 as part of the Affordable Care Act. The new rules will require retail food establishments with 20 or more locations doing business under the same name to clearly post calorie counts. This includes sit-down restaurants, fast-food restaurants, bakeries, coffee shops and restaurant-type food in some grocery and convenience stores. Take-out and delivery foods, including pizza, food purchased at drive-through windows and food at self-serve salad or hot-food bars are also subject to the new requirements. Vending machine operators will also be required to clearly display calorie information on products by either listing them on the front of the package or on a sign or sticker near the food item or the selection button. The restaurants will have one year to comply with the new rules, while the vending machine operators will have two years. Jenn Harris, *Los Angeles Times,* "FDA Requires Calorie Counts for Cocktails, Theater Popcorn, Vended Food," Nov. 25, 2014, http://www.latimes.com/food/dailydish/la-dd-fda-restaurants-bars-vending-machines-display-calorie-counts-20141125-story.html

Texas Abortion Clinic Laws Challenged in Federal Appeals Court

The 5th Circuit Court of Appeals is currently reviewing a case that involves a portion of a Texas law that requires that any clinic performing abortions meet stringent, hospital-like medical standards. Before the law passed a year and a half ago, Texas had over 40 clinics statewide that provided abortions. Under the law's more stringent standards only 17 clinics remain open currently, and only 10 facilities would remain if the debated provision of the law were reinstated. The case before the 5th Circuit involves a controversial provision which requires all facilities, even those performing early-stage abortions and nonsurgical medicinal abortions, meet the construction, equipment and staffing standards of ambulatory surgery centers. Waivers were not granted for longstanding clinics with good safety records. The decision will likely turn on what constitutes an "undue burden"—the current test for abortion laws as established by the Supreme Court. The 5th Circuit is expected to hand down a decision within the next few months. The case, along with many others like it, poses issues that are likely to be argued before the Supreme Court in coming years. Erik Eckholm, *New York Times,* "Texas Abortion Clinic Rules Tested in Appeals Court", Jan. 7, 2015, http://www.nytimes.com/2015/01/08/us/texas-abortion-clinic-rules-tested-in-appeals-court.html

Connecticut Teen Continues Fight for Right to Make Own Medical Decisions

The Connecticut Supreme Court ruled against a patient's wishes to refuse surgery and chemotherapy to treat Hodgkin's lymphoma. The Court found the State of Connecticut could require the patient, Cassandra C., a 17-year-old girl, to undergo treatment. Cassandra's physicians testified that without treatment she will

die, but she has an 80-85% chance of survival with chemotherapy. While the Court refused to consider testimony of her maturity, this issue may resurface as Cassandra turns 18 years old this September. Samantha Masunaga, *Los Angeles Times*, "Connecticut Teen Fighting State Justices' Ruling on Forced Chemotherapy," Jan. 10, 2015, http://www.latimes.com/nation/la-na-teen-chemo-20150111-story.html

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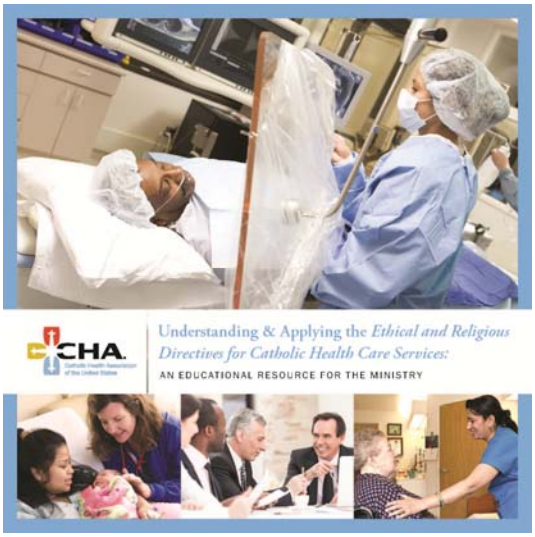

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Health Care Ethics USA

Health Care Ethics USA © 2015 is published quarterly by the Catholic Health Association of the United States (CHA) and the Albert Gnaegi Center for Health Care Ethics (CHCE) at Saint Louis University.

Subscriptions to *Health Care Ethics USA* are free to members of CHA and the Catholic health ministry.

Executive editor: Ron Hamel, Ph.D., CHA senior ethicist, retired

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Layout design: Jennifer Harris, CHA communications specialist

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