

## BIOETHICS

LISA SOWLE CAHILL

*Scholars and the public are well aware of the ethically controversial nature of euthanasia, artificial nutrition and hydration, and embryonic stem cell research. Moral theologians have extensively analyzed these issues, and religious leaders have publicly made them tests of orthodoxy. Literature on death and dying is therefore the main concern of this article, which also covers the literature on economic exclusion from adequate care at the end of life, low availability of hospice care, and inequities in global health resources.*

IN THE PAST FEW YEARS, appropriate care for the dying and stem cell research have been central to the bioethics literature.<sup>1</sup> Attention to the dying process follows liberalized euthanasia policy (in Oregon, the Netherlands, and Belgium) and a 2004 allocution of John Paul II mandating artificial nutrition and hydration of patients in a “persistent vegetative state.” The visibility of stem cell research has been raised by advocacy for expanded U.S. government funding. Stem cell research is of immediate concern primarily to the privileged—yet commands a disproportionate share of bioethical analysis. The ethics of death and dying affects everyone at some time. The ethics of dying is the central focus of this article. But stem cell research usefully highlights inequities in health resources that affect the way many meet death, especially from preventable diseases.

Since 2001, the U.S. government has barred federal funding to create embryos for research or to derive new cell lines from embryos, while permitting use of stem cell lines already in existence.<sup>2</sup> Yet private stem cell

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<sup>1</sup> The last “Moral Notes” review of bioethics was Maura A. Ryan’s “Beyond a Western Bioethics,” *Theological Studies* 65 (2004) 158–77. I will concentrate on periodical contributions from 2003 to 2005, and do not pretend comprehensiveness.

<sup>2</sup> See Cynthia B. Cohen, “Stem Cell Research in the U.S. after the President’s Speech of August 2001,” *Kennedy Institute of Ethics Journal* 14 (2004) 97–114;

institutes and public-private ventures at the state level are in the process of development. These would fund creation of research embryos and stem cell research, and would solicit private investment. The leader is California, where in 2004 voters passed a referendum committing \$300 million of taxpayers' money a year, for a decade, to a state stem cell research institute, without any guarantee that revenues would flow back into state programs.<sup>3</sup> In April 2005, the U.S. National Academy of Sciences issued ethics guidelines for stem cell research stating that creation of research embryos is acceptable, including embryos made from combined human and animal gametes, as long as they do not involve primates, and are not grown longer than 14 days.<sup>4</sup> Yet, in March 2005, the 191 members of the U.N. General Assembly backed a committee resolution calling nations to ban all human cloning (including "therapeutic cloning" to obtain embryonic stem cells). Supported by the U.S.A. and strongly contested by Belgium, Britain, and China, the vote was split 84 to 34, with 37 abstentions.<sup>5</sup>

Most critical analysis centers on the moral status of embryos.<sup>6</sup> Theolo-

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Gerard Magill, "Science, Ethics, and Policy: Relating Human Genomics to Embryonic Stem-Cell Research and Therapeutic Cloning," in *Genetics and Ethics: An Interdisciplinary Study*, ed. Gerard Magill (Saint Louis: Saint Louis University, 2004) 253–84; and Christopher Kaczor, *The Edge of Life: Human Dignity and Contemporary Bioethics* (Dordrecht: Springer, 2005) especially chap. 5, "An Ethical Assessment of Bush's Guidelines for Stem Cell Research" 83–96.

<sup>3</sup> See Daniel Callahan, "Promises, Promises: Is Embryonic Stem-Cell Research Sound Public Policy?" *Commonweal* 132 (January 14, 2005) 12–14; Debra Greenfield, "Impatient Proponents: What's Wrong with the California Stem Cell and Cures Act?" and David Magnus, "Stem Cell Research Should Be More Than a Promise," *Hastings Center Report* 34.5 (2004) 32–35 and 35–36.

<sup>4</sup> National Academy of Sciences, Committee on Guidelines for Human Embryonic Stem Cell Research, *Guidelines for Human Embryonic Stem Cell Research* (Washington: National Academies, 2005), available online at <http://books.nap.edu/catalog/11278.html> (accessed September 22, 2005).

<sup>5</sup> United Nations General Assembly, "United Nations Declaration on Human Cloning," *National Catholic Bioethics Quarterly* 5 (2005) 357–58. See LeRoy Walters, "Human Embryonic Stem Cell Research: An Intercultural Perspective," *Kennedy Institute of Ethics Journal* 14 (2004) 3–38.

<sup>6</sup> For an interdisciplinary debate that includes several theologians, the majority Catholic, consult Nancy E. Snow, ed., *Stem Cell Research: New Frontiers in Science and Ethics* (Notre Dame: University of Notre Dame, 2003). Other works include Brent Waters and Ronald Cole-Turner, ed., *God and the Embryo: Religious Voices on Stem Cells and Cloning* (Washington: Georgetown University, 2003); Suzanne Holland, Karen Lebacqz, and Laurie Zoloth, ed., *The Human Embryonic Stem Cell Debate: Science, Ethics, and Public Policy* (Cambridge, Mass.: MIT, 2001); Thomas A. Shannon and James J. Walter, *The New Genetic Medicine: Theological and Ethical Reflections* (Lanham, Md.: Rowman & Littlefield, 2003); William Fitzpatrick, "Surplus Embryos, Nonreproductive Cloning, and the Intend/Foresee Distinction," *Hastings Center Report* 33.3 (2003) 29–36; Paul Lauritzen, "Stem Cells,

gians, especially Catholic theologians, tend to be “conservative” in comparison to scientists and investors. Much theological debate concerns whether the embryo has significant or even full “personal” status at conception, or whether it has lesser status until 14 days, the point at which “individuality” is established, and survival, if implanted, is much more likely. Another question is whether, even if an embryo is not a “person,” it still has status sufficient to prohibit the creation of research embryos.<sup>7</sup> Some propose producing stem cells from entities similar to embryos, but lacking potential to become human individuals.<sup>8</sup>

The exact status of embryos is unlikely to be settled very soon. However, there could and should be agreement among theological bioethicists to bring a justice lens to stem cell research and the anticipated profits that largely motivate it.

Terminal illness and dying are of more acute global significance than genetic innovations. Physician-assisted suicide has been legal in Oregon since 1997. In 2002, the Netherlands and Belgium implemented legislation permitting direct euthanasia, making those two countries a testing ground for the social implications of normalizing medically assisted killing. Like stem cell debates, these discussions assume the availability of modern medicine. They are irrelevant for much of the world’s population. Yet the concerns of theology and ethics as they pertain to health, illness, and death should be relevant to everyone.

Beyond euthanasia and artificial nutrition and hydration, bioethics, es-

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Biotechnology, and Human Rights: Implications for a Posthuman Future,” *Hastings Center Report* 35.2 (2005) 25–33; Bart Hansen and Paul Schotsmans, “Stem Cell Research: A Theological Interpretation,” *Ephemerides theologicae Lovanienses* 80 (2004) 339–72.

<sup>7</sup> This is not a new debate. See Thomas A. Shannon and Alan B. Wolter, “Reflections on the Moral Status of the Pre-embryo,” *Theological Studies* 51 (1990) 603–26, also included in James J. Walter and Thomas A. Shannon, *Contemporary Issues in Bioethics: A Catholic Perspective* (Lanham, Md.: Rowman & Littlefield, forthcoming); Waters and Cole-Turner, *God and the Embryo*; and a special focus on “The Embryo Question,” *New Atlantis* 7 (Fall 2004/Winter 2005) 99–131.

<sup>8</sup> See President’s Council on Bioethics, *White Paper: Alternative Sources of Pluripotent Stem Cells* (Washington: President’s Council on Bioethics, May 2005), available at [http://www.bioethics.gov/reports/white\\_paper/index.html](http://www.bioethics.gov/reports/white_paper/index.html) (accessed October 10, 2005); Joint Statement with Signatories, “Production of Pluripotent Stem Cells by Oocyte-Assisted Reprogramming,” and Edward J. Furton, “A Defense of Oocyte-Assisted Reprogramming,” both in *National Catholic Bioethics Quarterly* 5 (2005) 579–83 and 465–68, respectively; Joachim Huarte and Antoine Suarez, “On the Status of Parthenotes: Defining the Developmental Potentiality of a Human Embryo,” *National Catholic Bioethics Quarterly* 4 (2004) 755–70; and Paul J. Hoehner, “Altered Nuclear Transfer” and W. Malcolm Byrnes, “Why Human ‘Altered Nuclear Transfer’ is Unethical,” both in *National Catholic Bioethics Quarterly* 5 (2005) 261–70 and 271–79.

pecially theological bioethics, should pay attention to the fact that a leading cause of death worldwide is poverty, which deprives many of life-saving care considered routine in the more “developed” countries.<sup>9</sup> If bioethicists in prosperous cultures are to resolve issues of high global importance, they cannot limit themselves to advanced medical supports. Access to resources is integral to the ethics of death and dying, as well as of genetics.

Structural justice and solidarity receive more attention from theologians than from philosophers; Catholic bioethicists have a rich common good tradition on which to draw. Nevertheless, even Catholic bioethical literature has presented the ethics of death and dying, and of genetics and stem cell research, predominantly in terms of the rights of individual patients and embryos in modern facilities. In her 2004 “Moral Notes,” Maura Ryan urges that theological bioethics attend to global perspectives.<sup>10</sup> A projected 2008 “Moral Notes” contribution on AIDS will bring the health needs of the poor into focus in a striking way. But questions of justice also lie below the surface of debates about artificial nutrition and hydration, euthanasia, and genetics.

John Paul II issued many counsels on care for the dying and on respect for early life. He virtually always highlights economic conditions that make the health and well-being of many precarious. As President George W. Bush was considering national stem cell policy in 2001, it was widely reported that John Paul II warned him to protect human embryos. Much less frequently noted—even by Catholic commentators—was that the pope sounded that warning only after calling on Bush, as a world leader, to propel “a revolution of opportunity, in which all the world’s peoples actively contribute to economic prosperity and share in its fruits.” Respect for “equal dignity” and “human dignity” “demand policies aimed at enabling all peoples to have access to the means required to improve their lives.”<sup>11</sup>

John Paul’s address for the 2005 World Day of the Sick, held in Cameroon, compares contemporary Africa to the man who was assisted by Luke’s Good Samaritan. Africans “are lying, as it were, on the edge of the road, sick, injured, disabled, marginalized and abandoned.” Despite the continent’s vibrant cultures, too many suffer from “serious inadequacies in the health care sector” rooted in global callousness and exploitation.<sup>12</sup> He cites AIDS, malaria and tuberculosis, high-priced pharmaceuticals, war and

<sup>9</sup> See the 2005 U.N. Human Development Report at <http://hdr.undp.org/reports/global/2005/> (accessed September 22, 2005).

<sup>10</sup> Maura A. Ryan, “Beyond a Western Bioethics.”

<sup>11</sup> John Paul II, “Remarks to President Bush on Stem Cell Research,” *National Catholic Bioethics Quarterly* 1 (2001) 617–18.

<sup>12</sup> John Paul II, “Message for the Celebration of the 13th World Day of the Sick,” September 8, 2004, [http://www.vatican.va/holy\\_father/john\\_paulii/messages/sick](http://www.vatican.va/holy_father/john_paulii/messages/sick) (accessed September 22, 2005). See also John Paul II, “Address to Promote Health

conflict, the arms trade, and wretched subsistence in refugee camps. Global social issues and “bioethics” cannot easily be separated.

### Artificial Nutrition and Hydration

For at least two decades, in the United States, the ethics of care for persons who are permanently comatose or in a “persistent vegetative state” (PVS) has been controverted in court cases, and by bishops’ conferences and theologians. In 2005, the Florida case of Terry Schiavo drove debate over what constitutes the best interests of PVS patients and where current Catholic wisdom stands on appropriate treatment. Within Catholicism there is a long-standing tradition that no one is obligated to use “extraordinary” or disproportionate means of life support, evaluated in terms of the condition of the patient, the usefulness and burdensomeness of a treatment, and, to a lesser degree, cost. The primary decision-maker is the patient or family.<sup>13</sup> The most definitive statement to date on obligatory and nonobligatory life supports is the Vatican *Declaration on Euthanasia*.<sup>14</sup> It permits the refusal or withdrawal of treatment if “the investment in instruments and personnel is disproportionate to the results foreseen,” or if they “impose on the patient strain or suffering out of proportion with the benefits which he or she may gain.” Such a decision is not suicide or euthanasia, but “acceptance of the human condition,” avoidance of “a medical procedure disproportionate to the results that can be expected,” or “a desire not to impose excessive expense on the family or the community.”<sup>15</sup> It is permissible to use necessary dosages of drugs to relieve pain, even if so doing will shorten life.

In line with the *Declaration*, the current edition of the U.S. bishops’ *Ethical and Religious Directives for Catholic Health Care Services* states that there should be a presumption in favor of providing artificial nutrition and hydration (ANH) to sustain life “as long as this is of sufficient benefit

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Development based on Equity, Solidarity, and Charity,” November 6, 1997, [http://www.healthpastoral.org/wordsofpope/jpii05\\_en.htm](http://www.healthpastoral.org/wordsofpope/jpii05_en.htm) (accessed September 22, 2005).

<sup>13</sup> See Dolores L. Christie, *Last Rights: A Catholic Perspective on End-of-Life Decisions* (Lanham, Md.: Rowman & Littlefield, 2003); David F. Kelly, *Contemporary Catholic Health Care Ethics* (Washington: Georgetown University, 2004) 127–244; and John Berkman, “Medically Assisted Nutrition and Hydration: A Contextualization of Its Past and a Direction for Its Future,” *Thomist* 68 (2004) 69–104.

<sup>14</sup> Congregation for the Doctrine of the Faith (hereafter CDF), *Declaration on Euthanasia*, May 5, 1980 (Boston: St. Paul Editions, 1980). This document is also available in the *National Catholic Bioethics Quarterly* 1 (2004) 431–47.

<sup>15</sup> CDF, *Declaration on Euthanasia* 12.

to outweigh the burdens involved to the patient.”<sup>16</sup> Whether it is truly a benefit to a PVS patient is identified as “requiring further reflection.”<sup>17</sup>

In March 2004, John Paul II delivered an “allocution” removing ANH from the category “medical procedure,” as mentioned in the *Declaration*, thus excluding it from estimates of proportionality. He calls ANH “a *natural means* of preserving life, not a *medical act*.” Therefore, “it should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory.” Withdrawal of ANH results in “death by starvation or dehydration.”<sup>18</sup> The pope clearly is concerned to protect vulnerable persons from utilitarian devaluation. Every person has “intrinsic value and personal dignity” and “a right to basic health care,” no matter what his or her “concrete circumstances.”<sup>19</sup>

Those who applaud the allocution reject any “quality of life” judgments, and see preservation of life as always a benefit. Richard Doerflinger regards “the decisive fact” underlined by the speech to be “the patient’s inherent dignity,” requiring preservation of life even without consciousness to support personal, interpersonal, or spiritual experiences and relationships.<sup>20</sup> Peter Cataldo argues that there is a duty to preserve life by nutrition, even if the capacity to strive for spiritual ends ceases, and even if life

<sup>16</sup> U.S. Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services* (Washington: United States Catholic Conference, 2001), available at <http://www.usccb.org/bishops/directives.shtml> (accessed September 24, 2005).

<sup>17</sup> *Ibid.*, introduction to part 5.

<sup>18</sup> John Paul II, “Address to the Participants in the International Congress on Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” March 20, 2004, *National Catholic Bioethics Quarterly* 4 (2004) 367–70, at 369 and 573–76, at 575 (original emphasis). The Autumn 2004 issue of the *NCBQ* carries articles and letters on this speech. The “Ethics” link on the Catholic Health Association’s website provides “Resources for Understanding Pope’s Allocution on Persons in a Persistent Vegetative State,” [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march/documents/hf\\_jp-ii\\_spe\\_20040320\\_congress-fiamc\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html) (accessed November 27, 2005). Critiques include: Thomas A. Shannon and James J. Walter “Implications of the Papal Allocution on Feeding Tubes,” *Hastings Center Report* 34.4 (2004) 18–20; Gerald D. Coleman, “Take and Eat: Morality and Medically Assisted Feeding,” *America* 190 (April 5, 2004) 16–20; Ronald Hamel and Michael Panicola, “Must We Preserve Life?” *America* 190 (April 19–26, 2004) 6–13; John F. Tuohey, “The Pope on PVS: Does JP II’s Statement Make the Grade?” *Commonweal* 131 (June 18, 2004) 10–12.

<sup>19</sup> John Paul II, “Address . . . on Life-Sustaining Treatments,” para. 4.

<sup>20</sup> Richard M. Doerflinger, “John Paul II on ‘The Vegetative State’: An Important Papal Speech,” *Ethics and Medics* 29.6 (2004) 2–4. Agreeing is Donald E. Henke, “A History of Ordinary and Extraordinary Means,” *National Catholic Bioethics Quarterly* 5 (2005) 575.

is a lower good.<sup>21</sup> Mark Latkovic even denies a hierarchy of spiritual goods over the good of life, since (following John Finnis and Germain Grisez) both are “basic” goods. Hence, tube feeding must be used unless it creates infections, the nutrients cannot be assimilated by the patient, or the patient is about to die.<sup>22</sup>

A contrary line is that biological life, without consciousness, does not furnish the opportunity to realize the interpersonal and spiritual goods that are life’s purpose, and is not worth preserving *to that individual*. Many follow an argument made in 1974 by Richard McCormick, who drew on a 1957 address of Pius XII to maintain that ability to sustain biological life alone does not make a treatment proportionate.<sup>23</sup> Just as Pius XII saw respirators to provide air as potentially extraordinary for some, so tubes providing food are analogous medical measures that might become disproportionate. In the absence of “relational potential” (i.e., the ability to participate meaningfully in human relationships) withdrawal is neither “suffocation” nor “starvation,” but the removal of a technology that does not serve the patient’s total welfare.

Nigel Biggar distinguishes merely biological from “biographical” life.<sup>24</sup> Belgian theologians Tom Meulenbergs and Paul Schotsmans argue that medicine averts death so that “patients might continue to pursue material, moral and spiritual values in some fashion that transcends physical life.”<sup>25</sup> While physical life is a real and true good in its own right, and not only because it is instrumental to “higher” purposes, it is also a *limited* good.<sup>26</sup> This means that quality of life may factor into decisions about the obligation to preserve life. Jason Eberl sees maintaining permanently unconscious patients by ANH as a type of “useless torture.” Due to the unity of

<sup>21</sup> Peter A. Cataldo, “John Paul II on Nutrition and Hydration,” *National Catholic Bioethics Quarterly* 4 (2004) 513–36, at 536. Cataldo maintains that the duty to preserve life has always been regarded independently of the presence of personal and spiritual capacities.

<sup>22</sup> Mark S. Latkovic, “A Critique of the View of Kevin O’Rourke, O.P.,” *National Catholic Bioethics Quarterly* 5 (2005) 512. Latkovic centers his argument around positions taken by O’Rourke in writing through 1999, and on more recent public oral statements.

<sup>23</sup> “Richard A. McCormick, “To Save or Let Die: The Dilemma of Modern Medicine,” *Journal of the American Medical Association* 229 (1974) 172–76; Pius XII, “Address to an International Congress of Anesthesiologists,” *National Catholic Bioethics Quarterly* 2 (2002) 309–14.

<sup>24</sup> Nigel Biggar, *Aiming to Kill: The Ethics of Suicide and Euthanasia* (Cleveland: Pilgrim, 2004) 56.

<sup>25</sup> Tom Meulenbergs and Paul Schotsmans, “The Sanctity of Autonomy? Transcending the Opposition between a Quality of Life and a Sanctity of Life Ethic,” in *Euthanasia and Palliative Care in the Low Countries*, ed. Paul Schotsmans and Tom Meulenbergs (Dudley, Mass.: Peeters, 2005) 135.

<sup>26</sup> *Ibid.* 137.

human nature and according to Aquinas, human ends must be pursued in light of the integration of body, intellect, and will, not physical existence only.<sup>27</sup> The overall condition and prospects of the patient constitute the criterion of care.

Kevin O'Rourke calls into question several premises underlying the 2004 papal allocution.<sup>28</sup> First is that widespread and published medical evidence need not be given serious consideration, while medical hypotheses of those promoting ANH are taken for granted. The likelihood of diagnostic errors or of recovery, or that withdrawal of ANH always causes suffering, is unsubstantiated and contradicts published scientific evidence. The assumption that removal of ANH is tantamount to "death by starvation" (thus Eugene Diamond<sup>29</sup>) implies wrongly that "the moral object of a human act is determined by the physical result of the action." It circumvents the central issue: whether ANH can be considered "a burden," "useless," or "disproportionate."

A group convened by the Canadian Catholic Bioethics Institute (CCBI)<sup>30</sup> reflects the impasse on this issue. It agrees that there is no absolute obligation to use ANH, since it has negative effects and few benefits for some patients, especially the frail elderly. Besides inability to assimilate the fluids and consequent bloating, effects include mental agitation, irritation, infection, bowel perforation, diarrhea, cramping, nausea, vomiting, blockage and leaking of the tube.<sup>31</sup> However, the "key question" of whether ANH can be truly a benefit for an unconscious patient, in the absence of these physical problems, was identified but not resolved. Theologians arguing that ANH is not beneficial for such patients do not deny that they have worth in themselves, have dignity, and are owed respect. The question is not whether such patients have rights or deserve care, but what kind of treatment genuinely respects their dignity.

<sup>27</sup> Jason T. Eberl, "Extraordinary Care and the Spiritual Goal of Life: A Defense of the View of Kevin O'Rourke, O.P.," *National Catholic Bioethics Quarterly* 5 (2005) 499–501.

<sup>28</sup> Kevin O'Rourke, "Reflections on the Papal Allocution concerning Care for PVS Patients," provided in manuscript by the author, and projected for publication in the *Journal of Christian Bioethics*.

<sup>29</sup> As in Eugene F. Diamond, M.D., "Assisted Nutrition and Hydration in Persistent Vegetative State," *Linacre Quarterly* 71.3 (2004) 199–205.

<sup>30</sup> The CCBI is lodged at St. Michael's College of the University of Toronto, with support from the Catholic Archdiocese of Toronto, <http://www.utoronto.ca/smikes/bioethics/> (accessed September 24, 2005).

<sup>31</sup> CCBI, "Reflections on Artificial Nutrition and Hydration," *National Catholic Bioethics Quarterly* 4 (2004) 773–82, at 780. See also Stephen G. Post, "Tube Feeding and Advanced Progressive Dementia," *Hastings Center Report* 31.1 (2001) 36–42. Post remarks, "'Terminal dehydration' and the analgesic effect it brings about appear to be a natural part of the dying process of many diseases" (39).

### The Schiavo Case

The debate over ANH was galvanized in the U.S.A. in March 2005. Theresa (Terri) Schindler Schiavo was 41 years old, had been in PVS for 15 years, and was receiving care in a Florida hospice. After review by 20 judges in nine courts, and six U.S. Supreme Court decisions not to intervene, feeding tubes were removed at the decision of Schiavo's husband, Michael Schiavo, and over the long-standing and vehement objections of her parents, Robert and Mary Schindler. As her death approached, Catholics, including bishops and Vatican representatives, hurled accusations of "murder" at Michael Schiavo, the courts, and participating medical personnel. After her death, family members continued to wrangle over funeral arrangements.

Many impugn the motives to withdraw ANH. Edward Furton calls the Schiavo outcome a "successful effort to kill this woman simply because she was disabled."<sup>32</sup> Robert P. George advises us not to "kid ourselves" that Michael Schiavo considered his wife anything but a "burden."<sup>33</sup> Yet others believe "this zeal to protect life has turned biological life into an idol."<sup>34</sup>

Substantively, the Schiavo debate has not moved the question much past John Paul II's allocution. The issue remains the determination of the best interests<sup>35</sup> of persons who by reasonable medical standards have virtually no potential to regain consciousness. Despite assertions that patient interests demand indefinitely prolonged ANH, few competent persons are rushing to sign advance directives stipulating such measures for themselves. In fact, the Florida bishops held up the Schiavo case to advise drawing up directives, but did not instruct the faithful to call for ANH when envisioning PVS.<sup>36</sup>

The Schiavo case does accentuate the problem of defining who is the primary determiner of best interests in cases of uncertainty or conflict.

<sup>32</sup> Edward J. Furton, "To the Editor," *Hastings Center Report* 35.3 (2005) 5. This issue contains several letters on the subject by theologians.

<sup>33</sup> Robert P. George, "When Treatment Is in Question," *Harvard Divinity Bulletin* 33 (Spring 2005) 16.

<sup>34</sup> Thomas A. Shannon, "The Legacy of the Schiavo Case," *America* 192 (June 6–13, 2005) 19.

<sup>35</sup> "Best interests" refers to the welfare of persons, considered as reasonably and objectively as possible. It is different from what a person in fact chooses, or could be predicted to choose, were he or she able ("substituted judgment"), since actual preferences and choices do not always meet the standard of objective moral defensibility. See Rebecca Dresser, "Schiavo's Legacy: The Need for an Objective Standard," *Hastings Center Report* 35.3 (2005) 20–22.

<sup>36</sup> Florida Catholic Conference, "Florida Bishops on Terri Schiavo," February 15, 2005, <http://www.flacathconf.org/Health/Schiavo%20Statement%202-15-05.htm> (accessed March 31, 2005).

Advance directives can assist, but are not a panacea. Designated proxies are a more flexible option. It is most imperative to provide optimum pastoral support to those facing stressful life-or-death decisions, so to resolve hostility and conflict.

Another angle of debate sharpened by the Schiavo case is the authority of the papal allocution. Some maintain it subverts Roman Catholic tradition and so lacks authority, others that it develops a new tradition and is authoritative, and still others that it can be accommodated within the long-standing tradition of permitting withdrawal of ANH if interpreted cautiously. In the first category are those depreciating the weight of the allocution due to its genre, absence of authoritative repetition, and lack of coherence with the prior consensus that relationships and spirituality define life's meaning. Commenting specifically on the Schiavo case, and reflecting a significant slice of the reactions to John Paul II's 2004 talk, John Paris offers that it and the court case must be interpreted in the light of a 400-year tradition on extraordinary or disproportionate means.<sup>37</sup> O'Rourke points out that one well-established criterion of the authority of a papal teaching, especially an allocution ("the least authoritative form of papal teaching"), is repetition. The views put forth in March 2004 were not subsequently reinforced by the pope, despite the fact that he gave further addresses on health, illness, and health care. Nor have they been reinforced or enforced by the Vatican or by the U.S. bishops, or been widely implemented in Catholic health care facilities.<sup>38</sup>

A second viewpoint is that the allocution departs from prior teaching, yet is quite consistent with emerging teaching, which the allocution furthers and solidifies. Some approve and others disapprove of this shift. Furton sees a number of documents since 1981 as preparing for a presumption in favor of food and water as part of ordinary care.<sup>39</sup> Shannon and Walter seem convinced, though with evident dismay. They identify a novel "deontological" method of stipulating duties with no regard for consequences that "undercuts the traditional burden-benefit method and risks imposing great hardship on patients and families at a time of great crisis."<sup>40</sup> A consequence has been the virtual restriction of the extraordinary-ordinary distinction to cases of imminent death; if death is not imminent (as in the Schiavo case), then life must be prolonged. Shannon and Walter cite *Evangelium vitae*, as well as a 1981 document of the Pontifical Council *Cor*

<sup>37</sup> John J. Paris, "To Feed or Not to Feed: Terri Schiavo and the Use of Artificial Nutrition and Fluids," *Southern Medical Journal* 98 (2005) 757.

<sup>38</sup> *Ibid.*

<sup>39</sup> Furton, "To the Editor" 5.

<sup>40</sup> Thomas A. Shannon and James J. Walter, "Assisted Nutrition and Hydration and the Catholic Tradition: The Case of Terri Schiavo," *Theological Studies* 66 (2005) 662.

*Unum* (*Questions of Ethics Regarding the Fatally Ill and the Dying*), a 1986 statement of the Committee on Pro-Life Activities of the National Conference of Catholic Bishops, a 1987 statement of the New Jersey Catholic Conference, and even the *Religious and Ethical Directives*, since the latter establishes a “presumption” in favor of ANH for “all patients.” In any event, Shannon and Walter argue, any widespread attempted implementation of such a policy in Catholic health facilities would be a disaster.<sup>41</sup>

A third group—of a more “conservative” bent—proposes a hermeneutic of cautious and strictly limited appropriation. Weight can be placed on the pope’s use of the term “in principle” to qualify or specify the obligation to view ANH as “ordinary or proportionate.” Mark Repenshek and John Paul Slosar construe this phrase to mean that “all other things being equal,” feeding tubes must be inserted for unconscious patients, but that this obligation is not exceptionless and does not hold if disproportionate “in the actual circumstances” of a given individual’s life.<sup>42</sup>

The CCBI statement notes that the pope’s phrase “in principle” does not mean “absolute,” that every patient has dignity, and that ANH need not be used if it is “overly burdensome, costly or otherwise complicated.”<sup>43</sup> John Berkman sees the obligation as relatively strong, but not absolute.<sup>44</sup> Philosopher Jorge Garcia concurs that the tradition, including this recent development, does not demand ANH in every case, although it puts the emphasis on sustaining life in case of doubt. He commends a “middle position” in which ANH might sometimes be declined.<sup>45</sup>

Scott McConaha discusses a 1998 address of John Paul II to U.S. bishops, “Building a Culture of Life.”<sup>46</sup> Here the pope differentiates “taking away the ordinary means of preserving life such as feeding, hydration and normal medical care” from “medical procedures that may be burdensome, dangerous or disproportionate to the expected outcome.” ANH should not be omitted intentionally to cause death, and “the presumption should be in favor of providing medically assisted nutrition and hydration to all patients

<sup>41</sup> Thomas A. Shannon and James J. Walter, “Implications of the Papal Allocution on Feeding Tubes,” *Hastings Center Report* 34.4 (2004) 18.

<sup>42</sup> Mark Repenshek and John Paul Slosar, “Medically Assisted Nutrition and Hydration: A Contribution to the Dialogue,” *Hastings Center Report* 34.6 (2004) 15.

<sup>43</sup> CCBI, “Reflections” 778.

<sup>44</sup> Berkman, “Medically Assisted Nutrition and Hydration.” Berkman points out that for frail but conscious patients, oral feeding may carry important interpersonal and sacramental significance.

<sup>45</sup> Jorge L. A. Garcia, “Understanding the Ethics of Artificially Providing Food and Water,” read in manuscript. This paper will appear in the *Linacre Quarterly* (2006), as well as in *Nutrition and Hydration: The New Catholic Debate*, ed. Christopher Tollefsen (Springer, forthcoming).

<sup>46</sup> Scott M. McConaha, “Artificial Nutrition and Hydration: Recent Changes in Understanding Obligations,” *Linacre Quarterly* 71.3 (2004) 217.

who need them.”<sup>47</sup> While this statement foreshadows the pope’s 2004 characterization of ANH as “ordinary care” and not a “medical” means, it more closely resembles the *Directives* in establishing a “presumption” in favor of use, and not a strict requirement. It is this nonabsolute bias that some interpreters of the 2004 allocution have sought to retain by stressing that its wording requires ANH “in principle,” which can be read to imply “not necessarily in all cases.”

Beyond individual quality of life, justice is relevant. Dan O’Brien, John Paul Slosar, and Anthony R. Tersigni applaud the pope’s repudiation of “utilitarian pessimism” about the severely incapacitated. Yet they agree with O’Rourke that ANH is a medical procedure, and that, in any event, “extraordinary means” are not restricted to “medical” means. They continue: “It could be argued that considerations of distributive justice, responsible stewardship, and the common good would require dedicating our health-care resources first to rectifying some of the fundamental inequities in the current structure of access to health care in this country [and others], before dedicating any resources to ‘awakening centers’ that may or may not have any impact on outcomes.”<sup>48</sup>

The contentious point remains whether a presumption amounts to an absolute duty or a conditioned duty, how narrowly conditioned, and whether either a strictly conditioned or an absolute duty has been incorporated into magisterial teaching at a high enough level of authority, and with enough clarity and consistency, to constitute a genuine, or even irreversible, shift in the meaning of end-of-life care. While a more restrictive interpretation has been developing over the past two and a half decades, this interpretation is not yet definitive and universal. In addition to ambiguity of wording in official documents, pluralism persists both in moral-theological interpretation and—equally if not more importantly—in health care practice, where one even finds a practical bias toward allowing ANH to be declined as not in the best interests of certain patients. The intrusion of a “new” competitor subtradition should not be underestimated. Yet the consensus, justified by diverse strategies, is against strict interpretation. The challenge is to bring these strands together around compassionate care, rather than exploiting differences to fuel divisive church politics.

<sup>47</sup> John Paul II, “Building a Culture of Life, Ad Limina Address to the Bishops of California, Nevada, and Hawaii,” *Origins* 28 (1998) 316, as cited by McConnaha, “Artificial Nutrition” 217.

<sup>48</sup> Dan O’Brien, John Paul Slosar, and Anthony R. Tersigni, “Utilitarian Pessimism, Human Dignity, and the Vegetative State,” *National Catholic Bioethics Quarterly* 4 (2004) 497–512, at 504, 511. They cite seven medical articles arguing that ANH is not always beneficial.

An egregious insistence on ANH in virtually every case may be intended to protect vulnerable persons from utilitarian cost-benefit calculations regarding the care appropriate for them. In reality, it is likely to enshrine inflexible regimes of “treatment” that few people would choose for themselves, that contradict best interests and humane care of the ill and dying, and that turn a blind eye to the real and immediate health needs of the many who cannot access even basic and useful care. It also distracts attention from holistic pastoral care for families. Leo Pessini terms procedures that extend the dying process uselessly “disthanasia,” and describes Brazilian legislation intended to protect the ability to refuse treatment and receive humane care.<sup>49</sup> Lack of flexible options to evade terminal imprisonment by medical technologies foments activism for euthanasia and physician-assisted suicide. Hospice care, palliative care, and euthanasia are the subjects of the next section.

### Euthanasia and Palliative Care

Compared with ANH, there is much less pluralism in theological bioethics about direct killing. The received consensus is that euthanasia and physician-assisted suicide (PAS) are not acceptable, especially as formal social policy. Faith communities and humanistic medicine should seek expert and adequate pain relief, spiritual care, and social support for all who face chronic illness or death.<sup>50</sup> These forms of care are a matter of social justice as well as of personal respect. Andrew Lustig demonstrates that common good, solidarity, justice, rights, and a preferential option for the poor define the context of John Paul II’s rejection of euthanasia.<sup>51</sup>

Euthanasia and PAS correspond to baffling human dilemmas and the genuine ambiguity of cultural and philosophical estimates of death. Marciano Vidal reflects that the experience of death is always of the death of the “other” and necessarily remains an enigma. Ethical appropriation of death consists in an attitude toward life, acceptance of life’s nondefinitive character, and trust in a power beyond life.<sup>52</sup> Christians must live within the

<sup>49</sup> Léo Pessini, “Distanásia: Algumas reflexões bioéticas a partir da realidade brasileira,” *Bioética* 12 (2004) 39–60.

<sup>50</sup>For perspectives beyond Christianity, see Neil Gillman, “Theological Reflections on the End of Life: A Theologian’s Address to Physicians,” *Conservative Judaism* 53.3 (2001) 17–26; G. Hussein Rassool, “Commentary: An Islamic Perspective,” *Journal of Advanced Nursing* 46 (2004) 281–83; Susan Orpett Long, “Ancestors, Computers, and Other Mixed Messages: Ambiguity and Euthanasia in Japan,” *Cambridge Quarterly of Healthcare Ethics* 10 (2001) 62–71.

<sup>51</sup> Andrew Lustig, “John Paul II on the Good of Life,” in *John Paul II’s Contribution to Catholic Bioethics*, ed. Christopher Tollefsen (Norwell, Mass.: Springer, 2004) 131–50.

<sup>52</sup> Marciano Vidal, “Apropiación ética de la muerte,” in *Bioética: Un diálogo*

dilemmas of mortality, offering company and fidelity to those ground down by illnesses with no medical solution.<sup>53</sup>

Successful initiatives to legalize euthanasia in Oregon, the Netherlands, and Belgium have faced virtually unanimous opposition by churches. Yet characterizations of euthanasia and PAS as “murder,” a violation of “the sanctity of life,” and “intrinsically evil acts” have not deterred advocates who see no real alternatives that meet people’s needs at life’s end. In fact, rhetoric about a “culture of death” can polarize public opinion so that religious messages against euthanasia are marginalized in “liberal” culture as ideological opposition to compassionate care.<sup>54</sup>

In 1997, Oregon’s Death with Dignity Act approved physician-assisted suicide, but not euthanasia. In 2001, the Dutch Parliament changed the penal code to allow both euthanasia and physician-assisted suicide, effective the next year. In 2002 the Belgian Parliament’s House of Representatives voted to legalize euthanasia. (It did not address PAS; suicide is not illegal in Belgium.) The Dutch debate on euthanasia is over two decades old; legal recognition merely formalizes accepted medical practice that had been technically against the law.<sup>55</sup>

According to the European Association for Palliative Care (EAPC), such care is scarce across Europe and available mostly to cancer patients.<sup>56</sup> Although euthanasia is common practice in the Netherlands, the Dutch are less familiar with options such as “do not resuscitate” orders, and the withdrawal of “extraordinary” means. In Belgium, by contrast, the eutha-

*plural*, ed. Jorge José Ferrer and Julio Luis Martínez (Madrid: Universidad Pontificia de Comillas, 2002) 221–33.

<sup>53</sup> Francesc Torralba Roselló, “Repensar la eutanasia: Crítica y deconstrucción de tópicos,” in *Bioética* 185–200. For a sensitive and provocative rendering of these ambiguities, see Margaret Pabst Battin, *Ending Life: Ethics and the Way We Die* (New York: Oxford University, 2005).

<sup>54</sup> Brian Doyle, “Killing Yourself: Physician-Assisted Suicide in Oregon,” in *American Catholics, American Culture: Tradition and Resistance*, ed. Margaret O’Brien Steinfels (Lanham, Md.: Rowman & Littlefield, 2004) 76–98. On the “liberal” biases operative among Oregon PAS activists, see Robert P. Jones, “Cultural Bias and Liberal Neutrality: Reconsidering the Relationship between Religion and Liberalism through the Lens of the Physician-Assisted Suicide Debate,” *Journal of the Society of Christian Ethics* 22 (2002) 229–63.

<sup>55</sup> See Paul Schotsmans and Tom Meulenbergs, ed., *Euthanasia and Palliative Care in the Low Countries* (Leuven: Peeters, 2005); and Jan Jans, “The Belgian ‘Act of Euthanasia’: Clarifying the Context, Legislation, and Practice from an Ethical Point of View,” *Journal of the Society of Christian Ethics* 25 (2005) 163–77. The majority of contributors to this volume are Catholic theologians and philosophers.

<sup>56</sup> Lars Johan Materstvedt, David Clark, John Ellershaw, et al., “Euthanasia and Physician-Assisted Suicide: A View from an EAPC Ethics Task Force,” *Palliative Medicine* 17 (2003) 97, available at <http://www.eapcnet.org/projectsethicshistory.asp> (accessed July 11, 2005).

nasia discussion developed in tandem with public and professional attention to the availability of palliative care, and the process of developing regulation of euthanasia raised the profile of palliative care significantly.<sup>57</sup>

The EAPC Ethics Task Force accepts individual choices for euthanasia or PAS. Yet it notes several dangers that follow legalization. These include euthanasia to avoid distressing treatment in “the modern medical system,” pressure on vulnerable persons, the devaluation of palliative care, widening categories of candidates for euthanasia,<sup>58</sup> an increase in the incidence of voluntary and involuntary “medicalized killing,” and crises of conscience for individual healthcare professionals. The Task Force views the mainstreaming of palliative care as one of the most important deterrents to legalized euthanasia and PAS.<sup>59</sup>

The American College of Physicians-American Society of Internal Medicine (ACP-ASIM) shares these reservations about expanded legal access to PAS. “A broad right to physician-assisted suicide could undermine efforts to marshal the needed resources, and the will, to ensure humane and dignified care for all persons facing terminal illness or severe disability.”<sup>60</sup>

Euthanasia and PAS have been repudiated by many religious groups, especially the Catholic Church.<sup>61</sup> Yet a joint statement of Dutch Protestants was less emphatic than the Catholic bishops on the absolute unacceptability of euthanasia or suicide in any form. The Protestants maintain that the changed law goes “a step too far,” lacking adequate protections for the disabled and minors.<sup>62</sup> Religious groups unanimously champion the cause of better and more available palliative care. John Paul II calls for

<sup>57</sup> Bert Broeckaert and Rien Janssens, “Palliative Care and Euthanasia: Belgian and Dutch Perspectives,” in *Euthanasia and Palliative Care* 35–69.

<sup>58</sup> Stephen Drake, “Euthanasia Is Out of Control in the Netherlands,” *Hastings Center Report* 35.3 (2003) 53, discusses the so-called “Groningen protocol” whereby infants with serious medical conditions may be killed. See Eduard Verhagen and Pieter Sauer, “The Groningen Protocol—Euthanasia in Severely Ill Newborns,” *New England Journal of Medicine* 352 [2005] 959–62. Theo A. Boer contends that, while caution is necessary, the democratic political process in the Netherlands limits abuses (“After the Slippery Slope: Dutch Experiences on Regulating Active Euthanasia,” *Journal of the Society of Christian Ethics* 23 [2003] 225–42. David J. Mayo and Martin Gunderson reject paternalism on PAS for the disabled (“Vitalism Revitalized; Vulnerable Populations, Prejudice, and Physician-Assisted Death,” *Hastings Center Report* 32.4 [2002] 14–21.

<sup>59</sup> “Euthanasia and Physician-Assisted Suicide” 99.

<sup>60</sup> Lois Snyder and Daniel P. Sulmasy, “Physician-Assisted Suicide,” *Annals of Internal Medicine* 135 (2001) 209–16. Sulmasy is a physician and theologian.

<sup>61</sup> See Jan Jans, “Churches in the Low Countries on Euthanasia: Background, Argumentation, and Commentary,” in *Euthanasia and Palliative Care* 175–204.

<sup>62</sup> *Ibid.* 183.

expert and specialized pain relief, especially when “proportionate and effective treatment is no longer possible.”<sup>63</sup>

The task for theological bioethics is not simply to make the abstract case that direct killing of the innocent is always wrong, or that the principle of double effect precludes directly intending their deaths. To say that life is a gift does not erase human responsibility and the need to lay conditions for the gift’s use or relinquishment.<sup>64</sup> Christian support for the ill and dying must communicate concretely that “the human senses of dependence, remorse, and hope meet a God who can be trusted, even in the midst of suffering and dying.”<sup>65</sup> The *Declaration on Euthanasia* portrays a request for euthanasia as “an anguished plea for help and love.”<sup>66</sup> The Reformed theologian Allen Verhey does not find an effective response to PAS or euthanasia in prohibitions, but in “a powerful and creative word of grace,” such as hospice.<sup>67</sup> Theological bioethics should focus on social conditions and health care that promote an environment where the very ill and dying can live out their remaining days with appropriate medical attention, without pain, with dignity and companionship, and without excessive financial burdens on themselves or families.

Palliative care and hospice are grossly underutilized in the United States, even though professional and religious nonprofit organizations advocate them.<sup>68</sup> In late 2005, separate reports by the Hastings Center and the President’s Council on Bioethics agreed that care for elderly and dying

<sup>63</sup> John Paul II, “To the Participants in the 19th International Conference of the Pontifical Council for Pastoral Health Care,” *National Catholic Bioethics Quarterly* 5 (2005) 154–55.

<sup>64</sup> Jan Jans, “Churches in the Low Countries on Euthanasia” 200–1.

<sup>65</sup> Allen Verhey, *Reading the Bible in the Strange World of Medicine* (Grand Rapids: Eerdmans, 2003) 320.

<sup>66</sup> CDF, *Declaration on Euthanasia* 9.

<sup>67</sup> Verhey, *Reading the Bible* 320.

<sup>68</sup> See Henk ten Have and David Clark, ed., *The Ethics of Palliative Care: European Perspectives* (Philadelphia: Open University, 2002); and Bruce Jennings, True Ryndes, Carol D’Onofrio, and Mary Ann Baily, *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, Special Supplement, *Hastings Center Report*, March–April 2003. For resources consult the National Hospice and Palliative Care Organization, <http://www.nhpco.org/templates/1/homepage.cfm>; and the Catholic-sponsored Supportive Care of the Dying: A Coalition for Compassionate Care, at <http://www.careofdying.org/>; also available through the Catholic Hospital Association’s links at <http://www.chausa.org/> under Continuing Care Ministries (accessed 9/29/05). See also Chris Gastmans, “Caring for a Dignified End of Life in a Christian Health Care Institution: The View of Caritas Catholica Flanders,” in *Euthanasia and Palliative Care* 204–25; Kathryn A. Holewa and John P. Higgins, “Palliative Care—The Empowering Alternative: A Roman Catholic Perspective,” *Trinity Journal* 24 (2003) 207–19.

patients must be targeted for reform. An excessive medical and legal focus on individuals, lack of access to hospice until late in the dying process, lack of support for families and for cooperative decision-making, inadequate long-term care, and dwindling numbers of care-givers, all contribute to dismal end-of-life prospects.<sup>69</sup> According to the ACP-ASIM, “Our societal emphasis on ‘cure’ and the medical emphasis on intervention have sometimes been at the expense of good end-of-life care. We have been slow to embrace the practice and principles of hospice, and dissemination of state-of-the-art palliative care, especially pain control techniques, has been incomplete.”<sup>70</sup>

### Suffering

Intractable suffering that grinds into body and spirit contributes to the cry for PAS. Suffering can torment and dissolve coherent agency and deface relationships through which a person clings to a niche in the world. Equally terrifying is the inexorable slide into the self-loss of Alzheimer’s.<sup>71</sup> Although we try to prevent, alleviate, or transmute suffering, it sometimes cannot be controlled; it must be accepted yet always resisted.<sup>72</sup>

Roger Burggraave forbids us to glorify or exaggerate the spiritual potential of suffering: “in physical and psychosomatic suffering . . . the ‘being delivered and chained to one’s own being’ . . . is experienced as violence: I feel myself gripped and overwhelmed by the ‘other’; I become, as it were, crushed in myself, paralysed and reduced to a thing.”<sup>73</sup> Suffering is excessive, unbearable, and “filthy,” evil, a “downward spiral” that inspires fear and embodies it.<sup>74</sup> Suffering is a consequence of humanity’s sin, is an

<sup>69</sup> President’s Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society* (Washington: President’s Council on Bioethics, September 2005), available at [http://bioethicsprint.bioethics.gov/reports/taking\\_care](http://bioethicsprint.bioethics.gov/reports/taking_care) (accessed November 21, 2005); and Bruce Jennings, Thomas H. Murray, and Gregory A. Kaebnick, ed., *Improving End of Life Care: Why Has It Been So Difficult? A Hastings Center Special Report, Hastings Center Report* 35.6 (2005) 2–60, available at <http://www.thehastingscenter.org/research/healthcarepolicy8.asp> (accessed November 21, 2005).

<sup>70</sup> Snyder and Sulmasy, “Physician-Assisted Suicide” 209.

<sup>71</sup> Mary Jo Iozzo writes from experience of faithful caregiving and the inadequate response of the health care system (“The Writing on the Wall . . . Alzheimer Disease: A Daughter’s Look at Mom’s Faithful Care of Dad,” *Journal of Religion, Disability, and Health*, forthcoming).

<sup>72</sup> Javier Barbero Gutiérrez, “Del ser al deber ser: Experiencia de sufrimiento y responsabilidad moral en el ámbito clínico,” in *Bioética* 888.

<sup>73</sup> Roger Burggraave, “You Shall Not Let Anyone Die Alone: Responsible Care for Suffering and Dying People,” in *Euthanasia and Palliative Care* 155.

<sup>74</sup> *Ibid.* 159.

undergoing of evil, is not caused by God, and is always terrible, even if the love of Christ encourages us to meet it with solidarity and hope.<sup>75</sup> The ethical response to suffering is not easy; there is no “solution” except “existing close to the other in his or her extreme vulnerability . . . and in ‘bearing’ the other.”<sup>76</sup> Jorge Garcia believes the battle “is difficult to exaggerate,” and cites the *Catechism of the Catholic Church*, John Paul II, and Benedict XVI in favor of a “preferential option for the sick.”<sup>77</sup> Some theologians invoke the Christian *ars moriendi* tradition to prepare for death; others counsel uniting one’s sufferings with Christ.<sup>78</sup> Yet the cultivation of virtues cannot ultimately insure the self against unpredictable and excessive distress. Practices of social, pastoral, and liturgical support should bind those alienated and isolated by suffering into communities of compassion, care, and belonging.<sup>79</sup>

### Palliative Sedation

The main reason why the very ill or dying suffer is lack of palliative care. However, in a very few cases even the best expertise fails to relieve the excruciating ravages of illness.<sup>80</sup> Catholic tradition has long recognized the permissibility of administering painkillers, including morphine at very high doses, to induce unconsciousness, at least for periods.<sup>81</sup> Any action directly intended to cause death can, in theory, be strictly differentiated from actions intended to relieve suffering, even if foreseeably shortening life, for example, through respiratory depression.

Experience, however, introduces a note of ambiguity into assessments of

<sup>75</sup> Brigid Vout, “The Way of Suicide, Assisted Suicide and Euthanasia, or *Evangelium Vitae*’s Way of Mercy and Compassion?” *Linacre Quarterly* 70.4 (2003) 301–15. Vout quotes John Paul II to the effect that suffering is terrible and that we rightly turn away from it.

<sup>76</sup> *Ibid.* 167.

<sup>77</sup> Jorge L. A. Garcia, “Sin and Suffering in a Catholic Understanding of Medical Ethics,” *Christian Bioethics*, forthcoming.

<sup>78</sup> See Christopher P. Vogt, *Patience, Compassion, Hope, and the Christian Art of Dying Well* (Lanham, Md.: Rowman & Littlefield, 2004); and “Practicing Patience, Compassion, and Hope at the End of Life: Mining the Passion of Jesus in Luke for a Christian Model of Dying Well,” *Journal of the Society of Christian Ethics* 24 (2004) 135–58; as well as Luke Gormally, “Pope John Paul II’s Teaching on Human Dignity and Its Implications for Bioethics,” in *John Paul II’s Contribution* 20–23.

<sup>79</sup> *Ibid.* 129–40.

<sup>80</sup> Gripping examples appear in David Barnard, Patricia Boston, Anna Towers, and Yanna Lambrinidou, *Crossing Over: Narratives of Palliative Care* (New York: Oxford University, 2000).

<sup>81</sup> A recent treatment is Peter A. Clark, “Morphine vs. ABT-594: A Reexamination of the Principle of Double Effect,” *Linacre Quarterly* 70.2 (2003) 109–20.

human intentionality in the complex and tragic sphere of terminal suffering. “Sometimes the effects of our action are too ‘close,’ morally speaking, to be told apart.”<sup>82</sup> One woman describes her role as surrogate decision-maker for her husband, dying from bone cancer that had metastasized to the brain. “‘At doses of 4 to 6 milligrams, my husband tossed and turned and his breathing was ragged. I asked for 10 milligrams and he began to choke. I asked the nurse to push the morphine pump to 30 milligrams and my husband died, no longer struggling, within two hours.’” On the face of it, this case fits neatly under double effect as an intention to do whatever necessary to subdue the loved one’s agony, accepting that the almost certain price is a shortening of life—“foreseen” but not “desired.” The wife’s self-examination, however, belies any simple verdict. “‘Did I kill him? I don’t know. Did I push the morphine pump up to warp speed to relieve his suffering or mine? I don’t know.’”<sup>83</sup>

Similar ambiguity can arise when “mercy-killing” (euthanasia) is contemplated, or “extraordinary” means are withdrawn. Margaret Farley remembers a young man dying of AIDS who realizes “it is time to concede,” and refuses further life-saving technologies. “Without erasing the difference between his form of letting go and a more active taking of his life, is it nonetheless possible that all the elements of religious acceptance could have been incorporated into one or the other?”<sup>84</sup> When a treatment is withdrawn, anticipating that death will follow immediately, a similar analytic quandary surfaces. Is it possible to dissociate the agent’s intention completely from the causation of death, particularly if death is also to be seen, in the words of the *Declaration on Euthanasia*, as “acceptance of the human condition”? Tangled together are the patient’s best interests, needs of family members and caregivers, and the “undesirability” of death, held in tandem with an acceptance that death is appropriate for this person at this time.

These factors beset the ethics of what is sometimes called “terminal sedation” or “palliative sedation.”<sup>85</sup> When pain and discomfort are extreme and persistent, unconsciousness is induced as a last resort, the rela-

<sup>82</sup> Biggar, *Aiming to Kill* 78.

<sup>83</sup> Christine Walker Campi, “When Dying Is as Hard as Birth,” *New York Times*, 5 January 1998, A19, as cited by Clark, “Morphine vs. ABT-594” 114–15. Campi is the executive director of Medical Mission International.

<sup>84</sup> Margaret A. Farley, “Issues in Contemporary Christian Ethics: The Choice of Death in a Medical Context,” *Santa Clara Lectures* 1.3 (1995) 14.

<sup>85</sup> See Robert D. Orr, M.D., “Just Put Me to Sleep . . . PLEASE! Ethical Issues in Palliative and ‘Terminal’ Sedation”; William Cutter, “Terminal Sedation: A Jewish Perspective”; and James J. Walter, “Terminal Sedation: Catholic Perspective,” all in the newsletter of Loma Linda University’s Ethics Center, *Update* 18.2 (2002) 1–12; Broekaert and Janssens, “Palliative Care and Euthanasia,”

tive immediacy of death is accepted, and ANH are typically not administered. The option of palliative sedation is one way to head off euthanasia, since it ensures that pain and related suffering can be avoided without causing death. It is important that all other routes have been explored. Muriel Gillick, an American doctor, comments that studies from the Netherlands show that about half of physicians studied have used terminal sedation to avoid suffering at the end of life, usually when death is expected to be imminent. Of these, 36% said they intended relief of symptoms not death, 17% said they did intend death, and 47% acknowledged both aims.<sup>86</sup>

The challenge to moral analysis derives from the fact that human intentionality and motives are often mixed. The ostensible incisiveness and clarity of double effect help stave off the kind of medically-sponsored expansion of killing that may already be occurring in the Netherlands. But human realities are often less clear than some uses of the principle suggest, and simplistic “condemnations” and “justifications” may not do them justice. The distinction of intentions regarding moral acts is surely intelligible, relevant, and important. But intentionality is not in every case clear-cut, and cannot bear the whole weight of the moral status of an act.

Theological bioethics should not approve the legalization of PAS or euthanasia. Nigel Biggar argues that, even if rare instances can be justified, legalization is dangerous.<sup>87</sup> Theologians and churches should strenuously advocate for palliative care and the right to refuse treatment, including ANH. Yet the case against euthanasia may be undermined rather than aided by an analytic framework that is not honest about complexities attending decisions taken on the far edge of life and *in extremis*.

### Compassionate Care and Exclusion

Most people fail to gain access to appropriate medical and palliative care at the end of life. The ethos of modern medicine is geared toward advanced technologies and away from accepting death. Moreover, many cannot access care, due to income, race, ethnicity, age, disability, and global location. Within disadvantaged groups, women more frequently suffer exclusion.

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in *Euthanasia and Palliative Care* 61–63; and Gastmans, “Caritas Catholica Flanders,” *ibid.* 211–12.

<sup>86</sup> Muriel Gillick, “Terminal Sedation: An Acceptable Exit Strategy?” *Annals of Internal Medicine* 241 (2004) 236–37. Broekaaert and Janssens confirm that in both the Netherlands and Flanders, there is a percentage of cases in which pain relief is intended by the doctors both to end pain and to terminate life (“Palliative Care and Euthanasia” 63). Gillick finds it troubling that, since palliative care consultation is seldom used in the Netherlands, many doctors may have elected terminal sedation when less drastic means were available.

<sup>87</sup> Biggar, *Aiming to Kill* 114, 164.

Health care exclusion already has been widely identified as a problem, both domestically and internationally.<sup>88</sup> Exclusion has acute consequences for those at the end of life. Inequalities can deprive people of opportunities “to continue with satisfactory social relationships and resolve social difficulties as they die.”<sup>89</sup> In the U.S.A, nonwhite and poorly educated people more frequently die in the hospital than at home, as most Americans prefer, because, lacking long-term care insurance, they go to emergency rooms when in crisis.<sup>90</sup> Minority groups may lack information about palliative care, and have little confidence that racially and culturally biased services will meet their needs.<sup>91</sup> All these problems are compounded for refugees.<sup>92</sup>

The elderly in all ethnic groups become special victims of discrimination when the medical system is focused on acute care, and because services are channeled toward the most economically productive. The elderly can lack a voice in which to advocate for themselves. A Dutch author questions whether traditional social solidarity in health care still extends to the elderly, who are placing unprecedented strains on health systems. Though the Netherlands offers universal health care, there are waiting lists for services of most use to the elderly, such as nursing homes, home care, cataract surgery, and hip replacements.<sup>93</sup> Many of these same factors apply to disabled people.<sup>94</sup> Religious organizations and local churches, often partnering with secular social service agencies and state and federal pro-

<sup>88</sup> An extensive discussion goes beyond the scope of this article, but see Lisa Sowle Cahill, *Bioethics and the Common Good* (Milwaukee: Marquette University, 2003); and *Theological Bioethics: Justice, Participation, and Change* (Georgetown University, 2005); Zdravko Plantak, “Universal Access to Health Care and Religious Basis of Human Rights,” *Update* 20.2 (2005) 1–12; Aaron Mackler, “Jewish and Roman Catholic Approaches to Access to Health Care and Rationing,” in *Kennedy Institute of Ethics Journal* 11 (2001) 317–36; and David Novak, “A Jewish Argument for Socialized Medicine,” *Kennedy Institute of Ethics Journal* 13 (2003) 313–28.

<sup>89</sup> Malcolm Payne, “Social Class, Poverty, and Social Exclusion,” in *Death, Dying, and Social Differences*, ed. David Oliviere and Barbara Monroe (New York: Oxford University, 2004) 8. Oliviere is Director of Education and Training, and Monroe is Chief Executive of St. Christopher’s Hospice, London, the international leader in hospice care.

<sup>90</sup> *Ibid.* 17.

<sup>91</sup> Shirley Firth, “Minority Ethnic Communities and Religious Groups,” in *Death, Dying, and Social Differences* 29–30.

<sup>92</sup> Mary Blanche and Chris Endersby, “Refugees,” in *ibid* 149–63.

<sup>93</sup> Ruud ter Meulen, “Are There Limits to Solidarity with the Elderly?” in *Healthy Thoughts: European Perspectives on Health Care Ethics*, ed. R. K. Lie and Paul Schotsmans, with B. Hansen and T. Meulenbergs, co-ed. (Sterling, Va.: Peeters, 2002) 329–36.

<sup>94</sup> Ann McMurray, “Older People,” and Linda McEnhill, “Disability,” in *Death, Dying, and Social Differences* 63–77 and 97–118.

grams, can be successful advocates and innovators in community-based care.<sup>95</sup>

Every one of the above barriers to compassionate, expert care at the end of life is exacerbated in the global context—where “terminal” medical circumstances arise more frequently and earlier than in privileged societies. In contexts of generalized scarcity, suffering, and conflict, therapeutic and palliative care supported by medical professionals is virtually nonexistent. Paul Farmer and Nicole Gastineau Campos “interrogate” the assumptions of “first world” bioethics, considering that AIDS, malaria, and tuberculosis are the three leading infectious killers of adults in the poorest communities in the world. Farmer and Campos find an “absurd divorce” between real health dilemmas and “the professional commentary they spawn,” comparing the latter to Monty Python skits.<sup>96</sup> Citing the work of Brazilian liberation theologian Marcio Fabri dos Anjos, Farmer and Campos call for greater connection between research and “third world” therapeutics, urge “the systematic participation of the destitute sick,”<sup>97</sup> and challenge theologians to invest in turning this situation around.<sup>98</sup> Theological bioethicists should answer this plea to take a hand in reversing the conditions they negatively assess, by adopting a stance of “pragmatic solidarity,”<sup>99</sup> to “fulfill the right to health [care] and share the fruits of research with the world’s poorest communities.”<sup>100</sup>

This agenda is confirmed by representatives from Catholic bioethics institutes, in an international colloquium on “Globalization and the Culture of Life,” focused on the frail elderly and dying.<sup>101</sup> It reaffirms Catholic tradition against euthanasia, in favor of declining disproportionate treatments, and in support of palliative care for all. Yet these options are placed

<sup>95</sup> See, for example, Harold G. Koenig and Douglas Lawson, with Malcolm McConnell, *Faith in the Future: Healthcare, Aging, and the Role of Religion* (Philadelphia: Templeton Foundation, 2004); and Anna-Marie Madison and Brenda F. McGadney, “Collaboration of Churches and Service Providers: Meeting the Needs of Older African Americans,” *Journal of Religious Gerontology* 11.1 (2000) 23–37. Resources, networks, and advocacy opportunities can be found on the Catholic Hospital Association’s website, <http://www.chausa.org> (accessed October 4, 2005).

<sup>96</sup> Paul Farmer and Nicole Gastineau Campos, “Rethinking Medical Ethics: A View from Below,” *Developing World Bioethics* 4 (2004) 22. This entire issue of the journal is devoted to matters of global health resource distribution.

<sup>97</sup> *Ibid.* 17.

<sup>98</sup> *Ibid.* 36. See Marcio Fabri dos Anjos, “Medical Ethics in the Developing World: A Liberation Theology Perspective,” *Journal of Medicine and Philosophy* 21 (1996) 629–37.

<sup>99</sup> Farmer and Campos, “Rethinking Medical Ethics” 37.

<sup>100</sup> *Ibid.* 38.

<sup>101</sup> International Colloquium of Catholic Bioethics Institutes, “Globalization and the Culture of Life Consensus Statement,” *National Catholic Bioethics Quarterly* 4 (2004) 151–58.

in a larger justice framework: “the alleviation of material, social, and spiritual poverty of the frail elderly is a fundamental obligation that Catholic health care and Catholic bioethics must address, according to the preferential option of the poor.” It should incorporate “the participation of less affluent peoples and societies.”<sup>102</sup> Above all: “In applying the principle of the common good to the development of new technologies and research priorities, the needs of the less affluent are to be given priority.”<sup>103</sup>

These recommendations encapsulate the message of this article. Theological bioethics should strive to reshape domestic and international health policy through political participation, as well as through the traditional venues of scholarship and education. Theologians addressing bioethics have an opportunity and a responsibility to redefine the social agenda of the field to highlight compassionate care and to favor the needs of the poor. The specific issues of death and dying highlight the inequality and deprivation that plague access to health resources worldwide. To change this situation should be the first priority of theological bioethics.

<sup>102</sup> Ibid. 157.

<sup>103</sup> Ibid. 155.