

# ETHICS & MEDICS

MARCH 2019 VOLUME 44, NUMBER 3

A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

■ Also in this issue: "SOGI Training in Catholic Hospitals," by the Ethicists of the NCBC ■

## A CONTEMPORARY *ARS MORIENDI* FOR END-OF-LIFE CARE

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Few would disagree that approaching death constitutes one of the most stressful and pivotal moments of life. In a process so fraught with emotion, fear, and uncertainty, the role of medicine should be to bring structure, peace, and calm. Unfortunately, contemporary practices too often exacerbate the confusion and emotions while contributing to heightened discomfort for patient and family alike.

There was a time when the clergy, medical providers, philosophers, and individuals agreed on how to achieve a happy and holy death. In the fourteenth century, as a response to the horror of the black death, a document emerged that was accepted and adopted by these disparate parties. Translated as *the art of dying*, the *ars moriendi* was a set of common instructions and coaching tools to facilitate a peaceful transition for providers and patients alike. The work served as a historical antecedent to authors such as Elisabeth Kübler-Ross, who sought to build consensus about the way death and dying should be approached by the medical establishment and society at large. There are those who recognize that "death is a physiological process, but it is a psychological and spiritual one as well." They rightly assert that "a peaceful death is an ideal to which many people aspire, but it may be difficult to achieve."<sup>1</sup>

The contemporary world needs a new *ars moriendi* that articulates a triple aim: standardizing the service terms and definitions of hospice and palliative care, promoting early initiation of end-of-life services, and de-emphasizing

services provided by intensive care units (ICUs) and emergency departments. If consensus could coalesce around these three goals, the experience of death and dying could be significantly improved.

The new *ars* respects the dignity of human life through natural death; nothing in it is intended to hasten death or take away hope. Rather, by promoting standardization and mutual understanding among practitioners and health care consumers alike, dignity will be enhanced as futile care is curtailed and patients and practitioners better understand the role end-of-life services play in guiding the dying toward a peaceful death.

### Clarifying Terms and Definitions

The first objective of this contemporary *ars* is to reach common ground on what hospice and palliative care entail, how the terms should be used, and how best to communicate them among professionals and laypeople. Considerable confusion exists about the distinction between hospice and palliative care: "Palliative care is not well-understood by patients or clinicians . . . [and] most health care professionals erroneously equate palliative care with end-of-life care."<sup>2</sup> Moreover, "some physicians use palliative care only if curative treatment fails, because they equate it with hospice."<sup>3</sup>

Leonard Berry and colleagues propose that a general name such as *supportive care* would be helpful, since "discussing palliative care services with patients and their families is challenging because of uncertainty about disease progression, cultural differences, and the tension between truth-telling and preserving hope." Thus, "brand messaging for palliative care will be more effective for patients and more comfortable for clinicians if the narrative also focuses on living life to its fullest at all stages."<sup>4</sup>

This new *ars* would more clearly define palliative care as a precursor to hospice; it would see palliative care as a service that enables continued rehabilitation and recovery while focusing primarily on alleviating troubling symptoms and promoting quality of life. Conversely, the new *ars* would refine the definition of hospice as non-rehabilitative and focused instead on quality of death. Far from promoting hopelessness, this view of hospice makes considerable effort to prepare patients and their loved ones holistically for the end of vitality and for a holy and peaceful death.

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## Early Hospice and Palliative Care

Early enrollment in hospice and palliative care enables patients and families to holistically prepare for death. The proposed *ars* recognizes that the decision-making process cannot be forced. The ethical standard of patient autonomy must be respected. While the care team can make recommendations, such services cannot be mandatory, and providers must not browbeat patients and their surrogate decision makers into election.

Melissa Aldridge and colleagues suggest that a primary barrier to early adoption of hospice and palliative care is the misunderstanding among prescribing physicians. Physicians in the United States tend to order palliative care when a patient is already in the terminal stages of illness rather than earlier in disease progression. The authors surmise that a “fairly consistent conclusion was that students in US medical schools had very little to no training in palliative care and did not feel confident to handle situations that required palliative care consultation.”<sup>5</sup> Enhanced training in hospice and palliative care by specialists such as cardiologists, pulmonologists, and oncologists would improve physicians’ aptitude in discussing early election of services.

Early adoption of hospice and palliative care imparts a variety of benefits to the patient and family, including symptom control, a sense of community and support during the dying process, and a better understanding of what to expect. The medical system and society can also gain financial benefits from early adoption. As health care costs continue to rise and a larger proportion of the population lives longer into old age, opportunities to increase efficiency should be embraced.

## Reducing the Costs of Care

The final aim of the proposed *ars* is to reduce the cost of end-of-life care through the appropriate use of services. Again, the *ars* is not advocating the withdrawal of critical care simply for cost savings; the benefit sought is an end, not a means. The medical literature supports early adoption of end-of-life services as a tactic to reduce the cost and burden of hospital-based end-of-life care, with the intrinsic advantage that such a death may be more peaceful and palatable for patients and families alike.

Lin Wang and colleagues identify three services that drive up costs at the end of life: “Inpatient admissions, ICU admissions, and [emergency department] visits.” The authors show significant reductions in the utilization of those services when patients are enrolled early in palliative care. Specifically, they found a 17 percent reduction in inpatient hospital admissions and an 11 percent decrease in ICU admissions. Emergency department visits were higher in the intervention group than in the control group, but these did not translate into hospital admissions and were characterized as “treat and release.” The authors’ findings suggest that “health plan–provided case management in palliative care for Medicaid beneficiaries

lowers inpatient and ICU utilizations,” which translates into cost savings.<sup>6</sup>

Marie Bakitas and colleagues reviewed the cases of 207 veterans receiving care at a National Cancer Institute Center. The authors found that 80 percent died at home instead of in an institutional setting.<sup>7</sup> Research suggests that, in addition to the cost savings, home death contributes to a happy and peaceful death for many patients. Virginia LeBaron and colleagues interviewed clergy to determine their opinion on what constitutes a good versus a poor death. They found that a poor death is “characterized by separation, doubt, and isolation,” emotions which are often experienced in an institutional setting. Conversely, a good death is “characterized by wholeness and certainty,” which might be experienced at home with family.<sup>8</sup> Kathleen Bickel and colleagues found that patients and providers alike prefer death at home, surrounded by family and loved ones, as opposed to death in a hospital.<sup>9</sup>

The societal benefits attained by the pursuit of a new *ars moriendi* will improve efficiency in the health care system and reduce confusion among medical practitioners and patients regarding the course of the dying process. This, in turn, will lead to a better quality of death for the dying. Finally, the resulting cost savings will be highly beneficial as a greater proportion of the population lives longer into old age and requires more intensive end-of-life care.

## Notes

1. Carolyn M. Aldwin et al., *Health, Illness, and Optimal Aging: Biological and Psychosocial Perspectives* (New York: Springer, 2017), 391.
2. Mary K. Buss, Laura K. Rock, and Ellen P. McCarthy, “Understanding Palliative Care and Hospice: A Review for Primary Care Providers,” *Mayo Clinic Proceedings* 92.2 (February 2017): 281, doi: 10.1016/j.mayocp.2016.11.007.
3. Leonard L. Berry, Robyn Castellani, and Brad Stuart, “The Branding of Palliative Care,” *Journal of Oncology Practice* (January 2016): 48, doi: 10.1200/JOP.2015.008686.
4. *Ibid.*, 49.
5. Melissa D. Aldridge et al., “Education, Implementation, and Policy Barriers to Greater Integration of Palliative Care: A Literature Review,” *Palliative Medicine* 30.3 (March 2016): 228, doi: 10.1177/0269216315606645.
6. Lin Wang, Leslie Piet, and Catharine M. Kenworthy, “Association between Palliative Case Management and Utilization of Inpatient, Intensive Care Unit, Emergency Department, and Hospice in Medicaid Beneficiaries,” *American Journal of Hospice and Palliative Medicine* 32.2 (March 2015): 218, 219, doi: 10.1177/1049909113520067.
7. Marie A. Bakitas, “Early versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial,” *Journal of Clinical Oncology* 33.13 (March 2015): 1438, doi: 10.1200/JCO.2014.58.6362.
8. Virginia T. LeBaron et al., “Clergy Views on a Good versus a Poor Death: Ministry to the Terminally Ill,” *Journal of Palliative Medicine* 18.12 (December 2015): 1001, doi: 10.1089/jpm.2015.0176.
9. Kathleen E. Bickel et al., “Defining High-Quality Palliative Care in Oncology Practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement,” *Journal of Oncology Practice* 12.9 (September 2016): e828–e838, doi: 10.1200/JOP.2016.010686.

## SOGI TRAINING IN CATHOLIC HEALTH CARE

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Ethicists of the NCBC

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In response to activists' demands and new regulations and guidance, some Catholic health care institutions and systems have begun implementing mandatory sexual orientation and gender identity (SOGI) training programs for employees. The National Catholic Bioethics Center is concerned that such programs may be heavily influenced by, or adapted directly from, transgender advocacy organizations. If these programs fail to accurately reflect Catholic teaching, they can undermine the witness of the Church and create conflicts of conscience for many in Catholic health care.

### Catholic Witness

Catholic health care expresses and continues the healing ministry of Jesus Christ. Therefore, it must be animated by the spirit of Christ and guided by the moral tradition of the Church in all dimensions of its services. Thus, any SOGI training program implemented in a Catholic health care institution should integrate the full scope of Catholic teachings. This includes, first and foremost, the Catechism's teaching that people accept their sexual identity and that sexual difference and complementarity are ordered to the human good.<sup>1</sup>

Any SOGI training should also be grounded in a truly Catholic anthropology. Catholic teaching holds that the human person is a body-soul union and that sexual identity is a fixed and unchanging endowment of God that is manifested through the body. SOGI training ought to affirm these realities and not accept, either explicitly or implicitly, a dualistic ideology that proposes a "self" that is separate from the body.<sup>2</sup> In addition, the training should counter both the false premise that biological realities (chromosomes, genitalia, etc.) are irrelevant for understanding sexual identity and the notion that sex and gender are unconnected or fluid.

Any SOGI training in a Catholic institution should offer a proper understanding of dignity. Catholicism teaches that human dignity is grounded in our creation in the image of God as male and female. As the Catechism notes, "Man and woman have been *created*, which is to say, *willed* by God: on the one hand, in perfect equality as human persons; on the other, in their respective beings as man and woman. 'Being man' or 'being woman' is a reality which is good and willed by God: man and woman possess an inalienable dignity which comes to them immediately from God their Creator" (n. 369, original emphasis). This understanding of dignity should be emphasized, not secular approaches

that define *dignity* as affirming the perceptions that people have of themselves.

In addition, the doctrinal and moral resources in the *Ethical and Religious Directives for Catholic Health Care Services* should be employed to integrate all applicable Church teachings into any SOGI training program. Relevant directives include those that address respect for human dignity (n. 23), the integrity of the human body (n. 29), human fertility (n. 53), and the mission of Catholic health care (nn. 9 and 67).

### Avoiding the Affirmation of Transgender Ideology

Secular SOGI training programs are often designed by transgender advocacy organizations. If a Catholic health care institution or system were to uncritically adopt such a program, or key parts thereof, it could affirm or even advance transgender ideology. This can occur in a number of ways.

First, secular programs instruct employees to use the "preferred" names and pronouns of those who claim to be transgender. They also instruct employees to apologize if they use a "wrong" name or pronoun, and suggest "correcting" fellow employees who do the same. This is problematic because it encourages employees to affirm another's misguided beliefs, conveys legitimacy to false notions of human anthropology, and disregards employees who have religious or moral objections to transgender affirmation. Catholic institutions should not require personnel to use preferred pronouns or sex-specific identifiers that explicitly contradict the person's biological sex.<sup>3</sup> Good medical care does not require adopting a new set of pronouns.

Second, secular programs employ terminology and concepts that are constitutive of transgender ideology. Examples include use of *cisgender* in place of male or female, and *gender affirmation surgery* in place of sex-change operation. Further explicit, and possibly manipulative, examples can be found in the glossaries of advocacy groups that are referenced in some secular training programs. For example, the National LGBT Health Education Center states, "We avoid using the phrases 'biological male' and 'biological female' because . . . they may not reflect how a person identifies in regard to their gender."<sup>4</sup> Catholic health care institutions should avoid using or even referencing such language. While there may be legal or regulatory pressure to incorporate "industry standard" terms and data fields into electronic medical records, instructing employees to use such language in their professional and personal interactions raises significant concerns.<sup>5</sup>

Two further cautions deserve mention. First, some secular training programs draw on the so-called platinum rule—"Treat others in the way they wish to be treated"—and teach that employees, including clinicians, should follow this rule literally in treating persons claiming to be transgender. Compelling employees to treat patients as they wish to be treated affirms the ever-expanding notion of autonomy in health care (including Catholic health care)—that people should be given whatever they want, regardless of whether it is in their best medical interests. Second, SOGI terms and concepts are being used by state and local governments to



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## ETHICS & MEDICS

VOLUME 44, NUMBER 3

MARCH 2019

The views expressed here are those of the individual authors and may advance positions that have not yet been doctrinally settled. *Ethics & Medics* makes every effort to publish articles that are consonant with the magisterial teachings of the Catholic Church.

change anti-discrimination laws—often bypassing the legislative process. By uncritically adopting SOGI language and concepts in mandated employee training, Catholic institutions could implicitly affirm and advance these efforts.

### Clinical Realities

To the extent that they address clinical care, any SOGI training program in a Catholic institution should provide objective, evidence-based information about the medical realities associated with transgenderism. This is particularly important for clinicians. Secular training programs emphasize health disparities experienced by those who claim to be transgender; however, they often only identify “stigma” and “discrimination” as reasons for these disparities and fail to acknowledge that mental health conditions such as depression and dissociative disorders often underlie, or at least may contribute to, such disparities. These programs also state that transgender individuals experience higher rates of mental health conditions, HIV infection, and suicide, yet they do not identify why these realities exist or how they may be linked to transgenderism itself. These are glaring omissions given the fact that numerous studies demonstrate links between transgenderism and negative health outcomes.

Beyond basic, objective clinical information, a SOGI training program needs to address practical questions that face employees in Catholic health care. For example, how is the program related to institutional or system policies that address gender identity? What resources does the institution or system provide to clinicians to help them guide patients to suitable counseling that addresses the root causes of transgender perceptions? And what strategies does the institution or system provide to help clinicians best respond to patients seeking hormones, medications, or procedures that the clinician cannot in good conscience provide or that would, in the clinician’s medical judgment, work contrary to the patient’s best interests? The training also needs to address how the institution or system will support clinicians

and other employees who, for reasons of conscience and religious liberty, cannot affirm transgenderism by using preferred pronouns or by adopting transgender language and concepts. Overall, any training must offer guidance, drawn from the Catholic moral tradition, for navigating with integrity the realities of gender identity confusion in light of the integral well-being of persons.

Catholic health care institutions that uncritically adopt secular SOGI training programs are in fact promoting transgender ideology. The guidance typically offered by these programs—mandating “correct” pronoun usage in accord with personal preference and incorporating gender-fluid concepts and language—contradicts logic, basic biology, and Catholic anthropology. While gender ideology poses a grave threat to Catholic health care, it also offers an opportunity. Catholic health care should respond to this ideology by faithfully articulating and applying Church teachings in the areas of sexuality, embodiment, and dignity. It should also commit itself to formulating holistic approaches to care that respect persons in their biological reality, accompany them in their suffering, and bring them to authentic healing through Christian charity and compassion. We must not miss this opportunity.

### Notes

1. *Catechism*, n. 2333. See also US Conference of Catholic Bishops, “Gender Theory/Gender Ideology: Select Teaching Resources,” February 2, 2017, <http://www.usccb.org/>.
2. NCBC, “Brief Statement on Transgenderism,” *National Catholic Bioethics Center Quarterly* 16.4 (Winter 2016): 600–601. See also John A. Di Camillo, “Gender Transitioning and Catholic Health Care,” *National Catholic Bioethics Quarterly* 17.2 (Summer 2017): 219–220.
3. NCBC, “Statement on Transgenderism,” 602.
4. Fenway Health, *Glossary of LGBT Terms for Health Care Teams*, s.v. “biological male/female,” National LGBT Health Education Center, updated March 2018, <https://www.lgbthealtheducation.org/>.
5. See Fenway Health, “Landmark Decision by Department of Health and Human Services Will Reduce Disparities Experienced by LGBT People,” Fenway Focus, October 7, 2015, <http://fenwayfocus.org>.

