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

■ Also in this issue: “Reflections on Revising Part 2 of the *ERDs*,” by John F. Brehany ■

## PROTECTING PATIENT GOALS IN PALLIATIVE CARE AND HOSPICE

Marie T. Hilliard



Although palliative care and hospice are distinct programs with distinct methods of reimbursement, the recipient is often the same person, who transitions from palliative care into hospice care.<sup>1</sup> Both programs aim to improve quality of life for a person with a chronic or serious illness. Hospice is unique because death is anticipated from illness, usually within six months. Palliative care gives patients comfort whether they are in danger of death or not. Both programs focus on symptom relief. While palliative care programs provide therapeutic interventions that could be curative, hospice programs may withdraw these interventions because they are no longer appropriate for a patient who is dying.

There are undocumented claims of the use of opioids or terminal sedation in hospice programs as a method of relieving suffering but with the intent of hastening death.<sup>2</sup> If true, such practices would not be consistent with the mission of hospice or justified under the principle of double effect.<sup>3</sup> These abuses would undermine the purpose of these programs. While most such claims are anecdotal, societal factors give credence to these reports. Some fault societal forces that weaken respect for human life and dignity, as evident in the growing acceptance and legalization of physician-assisted death. Others identify an increased focus on a utilitarian ethic of health care that can lead to a loss of concern for the individual patient and his or her family.<sup>4</sup> There is growing evidence that the root cause of such concerns involves the complexities of achieving goal-oriented care, which requires interdisciplinary goals-of-care conversations. These complexities are fostered by significant changes in the method of health care delivery and financing, the organization of medical practices, and the granting of health care facility admitting privileges.

### A New Landscape

Gone are the days of the family doctor, reimbursed through fee-for-service insurance plans, who followed a family from birth until death regardless of the setting in which the patient was receiving care and who had an intimate understanding of the values and goals of the family. The fee-for-service model of health care,

with growing advances in expensive health care technologies and specializations, became not only financially unsustainable but deleterious to maintaining standards of specialized care.<sup>5</sup> No physician can be an expert in multiple specializations. Thus, the age of referral medicine arose, with the role of the family physician supplanted by what is now known as the primary care physician, certified in family or internal medicine, who is the gatekeeper to a panoply of specialists. Often these specialists are introduced to the patient and family for the first time during a hospitalization without the benefit of an in-depth history of the patients they serve.

Enter new systems of health care delivery in which facility-employed physicians or hospitalists have replaced the primary care physician with admitting and treatment privileges. Increasingly, the referral for palliative care or hospice is from the hospitalist, especially in facilities where the primary care physician is not given privileges to practice. The hospitalist may have little to no history with the family and may want palliative care or hospice providers to assist in the time-consuming, goal-oriented conversations with the patient and family.<sup>6</sup> Furthermore, in specialty-driven health care, where even primary care is delivered through a group-practice model, the patient may have less frequent contact with the physician ultimately responsible for his care.

This can be exacerbated by the growing shortage of primary care physicians. When a health care crisis occurs, especially with a life-altering or terminal diagnosis, a referral is made to either a palliative care or a hospice program. Not only the referring specialty practice, hospitalist, or primary care physician but also the program receiving the referral may be unclear about the values and goals of care of the patient and family. Not infrequently, all have had little opportunity, until this crisis, to engage in goals-of-care conversations with the patient and family.

Added to this is the utilitarian view in which health care decisions can be made on the basis of cost of care, reimbursement policies, penalties for patient readmission, and algorithms that attempt to predict months until death.<sup>7</sup> With managed care restrictions, justification for needed services becomes even more problematic.<sup>8</sup> What are termed “best practices” can be skewed toward discontinuance or refusal of costly unreimbursed acute care in favor of reduced care, sometimes euphemistically labeled “comfort care.”

End-of-life or hospice decisions can be made and dispatched by a series of checked boxes on an advance directive or an actionable order known as a physician’s orders for life-sustaining treatment (POLST), which may have little to do with the real-life dilemmas being faced by a patient and family.<sup>9</sup> These documents may put pressure on the provider to deny proportionately beneficial care on his or her own initiative or as a concession to the will of the patient or, worse, the emotionally and financially stressed family. Thus, an overinflated sense of patient autonomy may supersede the

obligation of the physician to provide medical care consistent with the best interests of the patient.

If ever there was the need for “in-the-moment” decision-making, it is when the real-life situation has little similarity to those anticipated by a prior-executed, cookie-cutter advance directive or POLST.<sup>10</sup> This is the moment when the interdisciplinary team, including specialists and the primary care physician, may be most helpful in assisting the palliative care or hospice team with appropriate treatment aims. However, with the growing focus on community-based (i.e., at home) palliative care programs, there can be confusion on how palliative care differs from hospice.<sup>11</sup> This can have a negative effect on primary care physicians’ referrals and limit their involvement in goals-of-care conversations.

Questions about palliative and hospice care represent one of the busiest areas of bioethical consultation at The National Catholic Bioethics Center. Families report that they are presented with a set of facts, often through a utilitarian lens, from a health care provider who may be meeting the patient for the first time. If guidance is given at all, it may be directed toward withdrawing even proportionately beneficial care, which in some situations may represent passive euthanasia.<sup>12</sup>

This dilemma is heightened by the fact that Medicare does not pay for ongoing long-term care, which is very expensive, while hospice is reimbursed. Hospice will not provide “treatment intended to cure your terminal illness and/or related conditions, . . . prescription drugs to cure your illness, . . . room and board, . . . [or] care you get as a hospital outpatient (as in an emergency room), care you get as a hospital inpatient, or ambulance transportation.”<sup>13</sup> If Hospice care is the only affordable option, and it does not provide proportionately beneficial care, the result can be implicitly intending premature death.

### Need for Collaboration

What can be done? Both palliative and hospice care have a tremendous potential for good. They are needed and must be supported, especially as an alternative to physician-assisted death. But as described here, numerous forces negatively affect these programs well beyond the problem of financing long-term care, which is a real need. Families should not be forced to divest their elderly loved ones of property and savings to provide long-term care, often ultimately paid for by Medicaid, which requires the patient to have exhausted financial resources before eligibility.<sup>14</sup> Nor should care be directed or withdrawn by previously executed checked boxes that have no real relevance to the situation faced.

Here rests the critical role of a collaborative team, including the primary care physician, referring specialists, and the palliative care or hospice physicians, who know the values and goals of the patient and family. Such knowledge is facilitated through goals-of-care conversations. If the referring physician for palliative care or hospice is not the patient’s primary care physician, he or she needs to be called when a referral is received. The role of the primary care physician, in a world of specializations, must remain secure.

Palliative care and hospice, when utilized together, need to be integrated programs in which the primary care physician is a key player. Here, within a collaborative interdisciplinary team, all palliative care and hospice should have its roots, where goals of care can be defined in terms of the family’s moral and religious sensibilities. This is where spiritual beliefs and needs can be assessed and met, and the patient and family can feel comfortable that their desire for

spiritual and sacramental ministries will be not only respected but honored. For Catholics there must be access to the sacraments of Penance, Holy Eucharist, and Anointing of the Sick, including, if death is imminent, the apostolic pardon, which removes all penalties for sin (purgatory).<sup>15</sup> These are great consolations for families when the patient and family are faced with the ultimate decision to withdraw treatment that has become disproportionately burdensome to any anticipated benefit to the patient.

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### Notes

1. A number of community-based palliative care programs are sponsored by hospice agencies. See Holly Vossell, “Amedisys Expanding Palliative Care Operations” *Hospice News*, September 25, 2020, <https://hospicenews.com/2020/09/25/amedisys-expanding-palliative-care-operations/>.
2. Ralph A. Capone et al., “The Rise of Stealth Euthanasia,” *Ethics & Medics* 38.6 (June 2013): 2–4; Ron Hamel, “Ethics—Palliative Care—Stealth Euthanasia?” *Health Progress* 95.1 (January–February 2014): 68–71.
3. Jordan Potter, “The Principle of Double Effect in End-of-Life Care,” *National Catholic Bioethics Quarterly* 15.3 (Autumn 2015): 515–529, doi: 10.5840/ncbq201515348.
4. Marie T. Hilliard, “Utilitarianism Impacting Care of Those with Disabilities and Those at Life’s End,” *Linacre Quarterly* 78.1 (February 2011): 59–71, doi: 10.1179/002436311803888474.
5. D. A. Barr, *Introduction to U.S. Health Policy: The Organization, Financing, and Delivery of Health Care in America*, 4th ed. (Baltimore: Johns Hopkins University Press, 2016), chap. 5.
6. Larry Beresford, “10 Things Hospitalists Need to Know about Palliative Care,” *The Hospitalist*, October 10, 2016, <https://www.the-hospitalist.org/hospitalist/article/121441/hospice-palliative-medicine/10-things-hospitalists-need-know-about>.
7. Melinda Beck, “Can a Death Predicting Algorithm Improve Care?” *Wall Street Journal*, December 2, 2016, <https://www.wsj.com/articles/can-a-death-predicting-algorithm-improve-care-1480702261>.
8. Debra S. Feldman et al., “Effects of Managed Care on Physician–Patient Relationships, Quality of Care, and the Ethical Practice of Medicine, A Physician Survey,” *Archives of Internal Medicine* 158.15 (August 10/24, 1998): 1626–1632, doi: 10.1001/archinte.158.15.1626.
9. Christian Brugger et al., “The POLST Paradigm and Form: Facts and Analysis,” *Linacre Quarterly* 80.2 (May 2013): 103–138, doi: 10.1179/0024363913Z.00000000027.
10. Rebecca L. Sudore and Terri R. Fried, “Redefining the ‘Planning’ in Advance Care Planning: Preparing for End-of-Life Decision Making,” *Annals of Internal Medicine* 153.4 (August 2010): 256–261, doi: 10.7326/0003-4819-153-4-201008170-00008.
11. Alexis Coulourides Kogan et al., “Engaging Primary Care Physicians to Refer Patients to Home-Based Palliative Is Challenging and Complicated,” *Palliative Medicine Reports* 1.1 (November 5, 2020): 259–263, doi: 10.1089/pmr.2020.0009.
12. Tadeusz Pacholczyk, “Towards Passive Euthanasia,” *Making Sense of Bioethics*, April 30, 2010, <https://www.ncbcenter.org/making-sense-of-bioethics-cms/column-058-towards-passive-euthanasia>.
13. Centers for Medicare and Medicaid Services, “Hospice Care,” accessed October 7, 2021, <https://www.medicare.gov/coverage/hospice-care>.
14. American Council on Aging, “Medicaid Eligibility: 2021 Income, Asset & Care Requirements for Nursing Homes & Long-Term Care,” February 8, 2021, <https://www.medicaidplanningassistance.org/medicaid-eligibility/>.
15. See Canon Law Society of America, *Code of Canon Law: Latin-English Edition* (Washington, DC: CLSA, 1999), can. 213. “The Christian faithful have the right to receive assistance from the sacred pastors out of the spiritual goods of the Church, especially the word of God and the sacraments.” For an explanation of the apostolic pardon, see Marie Hilliard, “The Gift of the Apostolic Pardon,” *Ethics & Medics* 45.8 (August 2020): 3–6, doi: 10.5840/em20204584.

## REFLECTIONS ON REVISING PART 2 OF THE *ERDs*

John F. Brehany



*Third in a series that reviews the current ERDs and reflects on what changes would be necessary or helpful in their next major revision.*

### Introduction to *ERDs* Part 2

The content in part 2 of the 1995 *ERDs*, “The Pastoral and Spiritual Responsibility of Catholic Health Care,” is more substantive than in any of the past editions. Its introduction covers three fundamental points. First, it begins by establishing pastoral and spiritual care on the deepest of common grounds—human dignity (as created in the image of God) and human destiny (communion with God in heaven), in and through Jesus Christ. Second, it emphasizes the integral place of pastoral care within Catholic health care, describing it comprehensively, as a range of spiritual services, from a listening presence to sacramental ministry. Third, it briefly notes some unique features of contemporary pastoral care, including shorter hospital stays and the diverse roles of priests, deacons, and laity who address a variety of distinct needs.

The majority of part 2’s thirteen directives cover sacramental ministry (dirs. 12–20). While these are relatively straightforward, they reflect important changes in the Church and health care after Vatican II, such as lay extraordinary ministers (dir. 14), the significant attention given to the sacrament of Anointing of the Sick (dir. 15), and norms for the reception of the sacraments of Eucharist, Penance, and Anointing of the Sick by Christians not in full communion with the Church (dir. 20). These core topics are bookended by directives addressing important organizational issues. Directives 10 and 11 cover the basic duty to provide pastoral care, the need for pastoral care staff to be adequately educated, and their need to collaborate with local parishes, clergy, and leaders of other faith communities. Directives 21 and 22 address the role of the bishop in the appointment of priests, deacons, and non-Catholic personnel to a Catholic hospital’s pastoral care staff and in the appointment of directors of pastoral care.

The placement of part 2 within the 1995 *ERDs* signals the importance of pastoral care. In past editions, directives on “Religious Care of Patients” always came at the end. The 1948, 1955, and 1971 editions addressed certain sacramental issues in a common order—Baptism, Eucharist, and Penance. And prior editions covered a few topics beyond sacramental ministry, including proper disposition of amputated limbs and burial of deceased babies.

### Reflections on Revising *ERDs* Part 2

While there have been many articles on pastoral and spiritual care over the years, few have focused specifically upon *ERDs* part 2. One that did, a 2009 article by Sr. Jean DeBlois, suggested six areas for improvement: (1) better recognition of the multiple venues in which Catholic health care is offered; (2) recognition

of the multiple ways pastoral care personnel serve beyond basic spiritual services; (3) the need for more education and professional development; (4) more representational diversity among pastoral care staff; (5) solutions for the dearth of priests, which affects sacramental ministry; and (6) greater support for funding or retaining pastoral care services when health ministry budgets are under stress.<sup>1</sup> Here, I will suggest other measures to improve the guidance in *ERDs* part 2 on the basis of some key developments in the world, in the Church, and in health care.

Some changes of note in the world include a decline in religious practice among Catholics as well as a decline in membership and practice within organized religions, especially in Western industrialized nations. This trend has been accompanied by a concomitant rise in various spiritualities untethered from Christianity and other traditional religions. One of the most important recent developments in the Church, in terms of applying and integrating the work of the Second Vatican Council, has been the emphasis on the New Evangelization throughout the last three pontificates. Finally, health care organizations have continued to evolve, with increasing numbers of skilled employees and administrators, including positions such as “directors of mission services and ethics” designed to support Catholic and mission identity in the new millennium.<sup>2</sup> Other changes include increasing health care delivery outside traditional hospital settings and new challenges posed by severe pandemics. Based in part on these developments, here are a few practical suggestions for helpful revisions to part 2.

### New Directives regarding Pastoral Care

First, COVID-19 has affected every dimension of health care financing and delivery, including pastoral care services. Threats to the health and well-being of priests, chaplains, and pastoral care staff are real. Still, it is essential that sacramental and pastoral care continue to be offered even in the midst of present and future pandemics. The next revision of the *ERDs* should call for all Catholic health ministries to have measures in place to ensure that the sacraments are not denied to patients and that pastoral care staff are adequately protected.

Second, the decline in religious faith and practice and the rise in alternative spiritualities have affected Catholic health ministries. With good motives and at times based on patient request, some pastoral care staff have offered “complementary alternative medicines” such as Reiki and have drawn upon new age spiritualities, practices, and beliefs. There has been important recent guidance on these issues by the USCCB Committee on Doctrine and in a joint document from two pontifical commissions.<sup>4</sup> The next major edition of the *ERDs* should incorporate this guidance to prevent conflicts in religious beliefs and Catholic identity and to address other important ethical questions about offering such practices in health care.<sup>5</sup>

Third, over the last twenty years, greater attention has come to be paid to the grief of couples who suffer early pregnancy losses.<sup>6</sup> Pastoral care programs and distinctive forms of outreach to such couples are growing.<sup>7</sup> While the needs are real and significant, there is no mention of this topic within the current edition of the *ERDs*. This is ironic because earlier editions addressed the distinct but related topics of the disposition of human remains in the case of miscarriages and stillbirths. Yet these topics were entirely dropped in the 1995 *ERDs*. Given the importance of these issues in pastoral care, the next edition of the *ERDs* should address this topic.



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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.

### New Guidance regarding Organizational Identity, Mission, and Culture

The second article in this series noted the importance of organizational ethics for Catholic health ministries as distinct from their social responsibilities. Organizational mission, spirituality, and culture are topics of great significance for Catholic health care, yet they have received practically no formal attention in the current edition of the *ERDs*. Of note, the term *evangelization* is not mentioned once in the 1995 *ERDs*.<sup>8</sup> This is ironic since one of the most distinctive developments in the papal Magisterium of the last fifty years has been the emphasis on evangelization, from Pope St. Paul VI's apostolic exhortation *Evangelii nuntiandi* (1975) to Pope St. John Paul II's *Redemptoris missio* (1990) to Pope Emeritus Benedict XVI's founding of the Pontifical Council for Promoting the New Evangelization (2011) to Pope Francis's encyclical *Evangelii gaudium* (2017). All these documents and popes have emphasized the need to be bold and courageous, to go beyond maintaining the status the Church has gained in the world, and to explicitly proclaim the identity, teaching, and mystery of Jesus Christ.

As a venerable ministry of the Catholic Church, health care organizations share in the mandate to evangelize. While they must find a manner and language to do so consistent with other duties and roles and avoid any taint of proselytism, Catholic health ministries nevertheless should strive to bear positive, explicit witness to the full Gospel of Jesus Christ and to facilitate an encounter with him. They can do this not only in the course of their daily work but in witnessing to all the Church's teachings on the sanctity of human life, on the human body and sexuality, and on social responsibilities. Explicit guidance on this effort and on the role of traditional and new leaders such as directors of mission services should support this effort.

Beyond evangelization itself, there are important steps that a Catholic health ministry can take to build an authentically Catholic culture among its employees. Some measures, no doubt, are in place, for example, in the presence of chapels and religious artwork. However, ways can and should be found to draw appropriate attention to key seasons, feasts, and memorials in the liturgical calendar to ensure that the ministry's sense of time is not dictated entirely

by the calendar or fiscal year. In addition, formal guidance in the area of prayer arguably would be of benefit. Some practice of prayer already exists. But in my experience, the habit of offering reflections before meetings is more common than Christian prayer. Yet if the maxim *lex orandi, lex credendi* retains its validity (and I believe that it does), then for Catholic health ministries to build organizational cultures animated by the Gospel and Catholic beliefs and practices, they must do more to integrate the forms and formulas of authentic Christian prayer. Formal guidance in the next edition of the *ERDs* can encourage this effort.

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#### Notes

1. Jean DeBlois, "Where the Ethical and Religious Directives Fall Short," *Health Progress* 90.3 (June 2009): 48–50. A prior commentary on the 1995 *ERDs* that deBlois co-authored with Kevin O'Rourke actually contained little substantive analysis of the new *ERD* part 2. Jean DeBlois and Kevin O'Rourke, "Safeguarding Patients' Dignity," *Health Progress* 76.5 (June 1995): 39–49.
2. Mary Kathryn Grant, "Mission at the Millennium: Catholic Healthcare Systems Are Beginning to Develop Professional Mission Leaders," *Health Progress* 80.2 (March–April 1999): 18–20.
3. US Conference of Catholic Bishops, *Guidelines for Evaluating Reiki as an Alternative Therapy* (March 25, 2009); and Pontifical Council for Culture and Pontifical Council for Interreligious Dialogue, *Jesus Christ the Bearer of the Water of Life: A Christian Reflection on the "New Age"* (2003).
4. Maria Marra Arvonio, "Cultural Competency, Autonomy, and Spiritual Conflicts Related to Reiki/CAM Therapies: Should Patients Be Informed?" *Linacre Quarterly* 81.1 (February 2014): 47–56, doi: 10.1179/2050854913Y.0000000007
5. Julie Schwieter Collazo, "The Quiet Grief of Miscarriage," *US Catholic*, October 18, 2016, <https://uscatholic.org/articles/201610/the-quiet-grief-of-miscarriage/>.
6. Gerard-Marie Anthony and Sabine Heisman, "A Merciful Response to Miscarriage and Stillbirth," *Ethics & Medics* 43.12 (December 2018): 1–2, doi: 10.5840/em2018431219.
8. For an important recent development in the *ERDs* with regard to the call to witness, see Ethicists of the NCBC, "An Introduction to the Sixth Edition of the *ERDs*," *Ethics & Medics* 44.1 (January 2019): 4, doi: 10.5840/em20194411.

