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Balancing Autonomy With Relationships

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In the summer of 2010, a retired Milwaukee physician and his wife committed suicide, a month after she was diagnosed with Alzheimer's disease and just days after their 53rd wedding anniversary. Their daughter and grandson, fearing the worst, discovered the bodies.¹

The suicides were shocking, but not unexpected. Over the years, the couple had discussed with family and close friends — and put in writing — their intentions and reasons. The husband kept a journal. For years, the couple had expressed their desire to die together. Neither wanted to live without the other, neither wanted to live in a long-term nursing facility, though the wife's health was reaching the point where she required more care than her husband could provide on his own in their home.

The manner of their deaths was planned based on information and advice the husband gathered over the years from books and from his sources in the medical community. Moreover, as a physician himself, he used his expertise to assist in the suicide of his wife. But did the wife act freely, with her own autonomy, when she and her husband ended their lives? To what degree was that pos-

sible, given her recent dementia diagnosis? And perhaps most important of all, what lasting effect did their decision have on family, friends, neighbors, colleagues?

This story exemplifies the complexities involved in discussing both rational suicide and the more specific situation of physician-assisted suicide. It also points out that despite proponents' claims to autonomy, the seemingly solitary nature of suicides nevertheless involves the lives of others.

Autonomy usually usurps the conversation regarding assisted death. In the 2012 election cycle, the Commonwealth of Massachusetts voted down a provision that sought to legalize physician-assisted suicide.² (See story on page 6). Proponents of physician-assisted suicide, as well as those who argue for the moral permissibility of rational suicide, most often appeal to the principle of individual autonomy. I argue that the moral assessment of suicide ought to expand beyond the singular principle of autonomy. More particularly, I suggest that the notions of family and community provide important elements for consideration that proponents of physician-assisted suicide too casually dismiss.

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ity of using its art and expertise to willfully and deliberately hasten a patient's death, it ventures far from its origins. At its core, the health care profession has an obligation to do exactly that — to care. Caring cannot be reduced to giving medication or performing a therapeutic intervention. The holistic care that has long distinguished Catholic health care stands as a model and a prophetic witness resisting the illusory promises of physician-assisted suicide.

THE SECULARIZATION OF MEDICINE

Moral theologian Richard A. McCormick, SJ, S.T.D., offered a critique on physician-assisted suicide in 1991, when initial attempts to legalize it failed in Washington state.³ In McCormick's rebuttal of the practice, he implicates the secularization of medicine. In the late 19th century and early in the 20th, modernization and standardization significantly impacted medical practices as new discoveries and the advancement of new medical technologies became standard features of the modern clinic. McCormick observes that this evolution led to the secularization of medicine — a term he identifies as the withdrawal or

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the divorcing of medicine as a profession from a moral tradition. As a result, the profession experienced a “growing pre-occupation with factors that are peripheral to and distract from care,” such as insurance premiums, the influence of economic principles, competition, governmental regulations and mandates, accountability structures, questions of liability and the like.⁴ McCormick concludes that practically, medicine has been reduced to a business.

When medicine too closely follows economic and business principles, the patient becomes a commodity in the transaction. Patients exert preferences in the clinic not unlike other consumers in similar service encounters in the marketplace. When individual preference becomes normative and there is no tradition in which to adjudicate

clinical judgments, then medical professionals overemphasize autonomy.⁵

Similarly, bioethicist Daniel Callahan, Ph.D., critically reflects how new claims have been made upon medicine due to an exaggerated emphasis on autonomy. Such claims rose to the surface in the 2012 Massachusetts ballot measure. Callahan observes that these claims, like those in physician-assisted suicide, envision that medicine “should be prepared to make its skills available to individuals to help them achieve their private vision of the good life. This puts medicine in the business of promoting the individualistic pursuit of general human happiness and well-being.”⁶

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SUICIDE AND ASPECTS OF JUSTICE

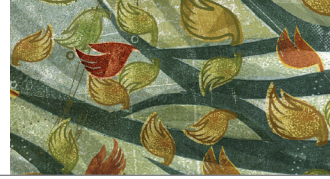
Oregon's 1997 “Death with Dignity” Act allows terminally ill patients to end their lives by taking medications prescribed for that purpose by a physician. The law requires the state's health authority to collect specific data and annually publish statistics about the patients and physicians who participate in physician-assisted suicide.

The latest report, published in January 2013, says that since the law was passed in 1997, “a total of 1,050 people have had DWDA prescriptions written, and 673 patients have died from ingesting medications prescribed under the DWDA.”⁷

“Prescriptions for lethal medications were written for 115 people during 2012 under the provisions of the DWDA, compared to 114 during 2011. At the time of this report, there were 77 known DWDA deaths during 2012.”

“As in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (93.5 percent), decreasing ability to participate in activities that made life enjoyable (92.2 percent), and loss of dignity (77.9 percent).”

Furthermore, of those invoking the “Death with Dignity” Act, more than 97 percent are white, and nearly two-thirds were formally educated with some college.⁸ These facts have led to critiques of physician-assisted suicide as a boutique service for the socially privileged.⁹ The leading reasons for requesting physician-assisted suicide



in Oregon entail concerns about physical symptoms in the future.¹⁰

When autonomy becomes the driving rationale, other important principles and virtues diminish — important virtues that have long shaped and ought to influence and persist in med-

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ical practice. Researchers have identified that among diverse racial and ethnic groups, considerations such as family and increased participation in faith communities override the autonomy paradigm. For example, Latinos less acutely fear being a burden on others as compared to whites.¹¹ These differing social values impact medical decision-making and end-of-life care.

Oregon physicians reported that those patients who described themselves as being a burden on family or caregivers as the reason for requesting assistance under the “Death with Dignity” Act increased from 12.5 percent in 1998 to nearly 45 percent 10 years later.¹² Yet the original argument for the bill’s passage was to provide a means to alleviate pain.

After just one decade, a driving rationale for physician-assisted suicide shifted from a desire to treat intractable pain to the use of lethal medications to alleviate feelings of burdensomeness. It is this feeling of being a burden and its social context that deserve reflection and consideration, particularly by those of us who understand health care as a ministry of Christ Jesus.

FROM RIGHTS TO RESPONSIBILITIES

Those who commit suicide or intentionally and willfully hasten their death violate commitments to their family and friends, if not also to the community. Individuals have a right to self-determination, and some wish to extend this right by arguing for a right to die — be it by suicide, physician-assisted death or euthanasia.

Rights, however, have corresponding duties. Yet in the autonomy-driven conversation prevalent in bioethics and in society, consideration of responsibilities is muted. An honest conversation on the topic of the right to suicide and

assisted death must explore the responsibilities patients maintain through the aging process and into terminal illnesses. Part of such conversation needs to sensitively account for mitigating factors like mental illness or coercive pressures that impinge upon one’s ability to fulfill duties and responsibilities.

The Milwaukee couple who died together in 2010 allegedly made their decision with clarity and left documentation attesting to this fact. Yet, in the note they left, they apologized to the people who would find them. At some level they knew their actions would be devastating to others. It is precisely this perspective of others — family, friends, loved ones and the wider community — that merits closer scrutiny.

As members of society, we have a duty to demonstrate an honorable and virtuous death for our loved ones and family members. Suicide undermines the family’s love and the opportunity for all involved to discover, explore and grow in love in the midst of vulnerability.

Some contend that suicide violates an obligation to live. This arises from the understanding that life is a gift. Gifts are things that are freely given. The receiver of a gift, in order to truly receive the object as a gift, must make some type of gift in return. A word of thanks or a bodily gesture of gratitude most simply fulfills this obligation.¹³

Life as gift requires some similar gesture of gratitude and reception. Theologian and ethicist Stanley Hauerwas, Ph.D., D.D., posits that “our obligation to sustain our lives even when they are treated with or require living with a horrible disease is our way of being faithful to the trust that has sustained us in health and now in illness. ... [I]t is our way of gesturing to those who care for us that we can be trusted and trust them even in our illness.”¹⁴

Hauerwas challenges the autonomy-driven argument of physician-assisted suicide by noting that the advancement of a right to die fundamentally rejects the trust in a patient’s caregivers, marriage vows, loved ones, community and society. When cures can no longer be offered, instead of placing one’s hope and trust in technologies and medical therapies, one must ultimately trust in the loving care of others.

The notion of a “good death” is one that Hauerwas describes as allowing our family and loved ones “to remember the dead in a morally healthy

way — that is, the manner of death does not prevent the living from remembering the manner and good of their life.”¹⁵

Stated differently, the individual seeking to hasten death has a duty to consider the harm done by the act. It is not simply an autonomous act performed in a vacuum. The action causes irreparable harm to others — to one’s family, to the person who finds the dead body, to those who lived next

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door or in adjoining apartments and potentially many more. The haunting memories can last for at least a generation, or, in the case of grandchildren, much longer. Viewed in light of this broader perspective, one more clearly discovers that suicide does not just involve an individual, but, rather, it entails a wider circle of influence.

INESCAPABLY A BURDEN

Hauerwas writes that suicide is, first, “a reminder that we have failed to embody as a community the commitment not to abandon one another.”¹⁶ Men and women naturally eschew the thought of being a burden on another. Yet, “it is only by recognizing that in fact we are inescapably a burden that we face the reality and opportunity of living truthfully.”¹⁷ We place burdens on one another time and again.

Despite this reality, our American culture praises individualism and strongly reinforces the illusion that we are self-supporting, independent creatures. Daily ordinary tasks rely upon the participation of others for things ranging from trash collection and food preparation to transportation and mass communications. Members of society are truly interdependent.¹⁸ Living in an interdependent society entails creating and sustaining bonds of trust. At times, men and women are able to give and contribute to society and to others. At other times, perhaps much more so than initially realized, they receive and benefit from the hard work and services of others. Through this asymmetrical ebb and flow of giving and receiving, “the value of human life does not depend only on its

capacity to give. Love, *agape* ...extends to ... those who have no value in their own eyes and seemly none for society. Such neighbor-love is costly and sacrificial. It is easily destroyed. In the giver it demands unlimited caring, in the recipient, absolute trust.”¹⁹

Health care professionals have the difficult yet necessary and privileged task of offering such unconditional acceptance to the patient. Loving care itself refutes the mindset of burdensomeness, which all too easily can take root in persons who are disabled, the elderly and the chronically and terminally ill. As the physician-assisted suicide debate has evolved in the U.S., it has become clear that its proponents have come to desire this option not primarily as a means to address intractable pain, but rather to more broadly address the experience of vulnerability and feelings of burdensomeness.

Nearly all health care professionals entered their work because of a desire to help others. Most health care professionals realize their personal calling to care for individuals, yet it cannot stop there. We live in communities and in webs of relationships. Our caring shapes society by virtue of the fact that individuals do not live in isolation. As health care professionals, we need to be more cognizant of the impact we have in shaping society’s perception of sickness, of illness, of aging, of disability and dying.

To conclude, I suggest that we cultivate the virtues in medicine and call it back to its roots in offering care and abiding with those suffering. I do not want to suggest that bioethics banish autonomy. Like all good things, it needs to be balanced. When medicine opens itself to the possibility of using its art and expertise to willfully and deliberately hasten a patient’s death, it ventures far from its origins. At its core, health care has an obligation to do exactly that — to care. A physician or nurse must offer care even when neither medicine nor therapy can cure.²⁰

As humans, we deeply long to be loved, to know that we are accepted, cherished and seen as important to others. When those with chronic and terminal illnesses experience a poverty of loving care, physician-assisted suicide becomes a tempting solution. Instead, we should challenge physician-assisted suicide with family, friends, support groups and the medical and mental health communities who should be able to create an environment that, at the very least, makes it difficult for



dependent individuals to perceive suicide as their very best option.

When members of society and faith communities foster relationships of deep, abiding love, then it becomes clearer that hastening death is not an exclusively autonomous act, but, rather, one that has an irreparable impact on others. Throughout life, even at its most agonizing moments, men and women maintain responsibilities to the relationships that have sustained them. The vulnerable are called to trust the love that others offer. Conversely, family and society must demonstrate that they worthily deserve such trust.

Family members, clinicians, and caregivers must strive to earn the trust of loved ones who bear the burdens of painful illness. Such trust arises out of a demonstrated commitment to bear those burdens together, and it is nurtured by the reassurance that comes from the selfless giving of authentic love.

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NOTES

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16. Hauerwas.
17. Hauerwas.
18. Alasdair MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues*, (Chicago: Open Court, 1999).
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