

Hospice Care and Assisted Suicide: A Crisis of Identity and Mission?

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In 2014, Courtney Campbell and Margaret Black wrote a very thorough and helpful analysis of how hospices in Oregon and Washington understand their mission vis-à-vis assisted suicide.¹ They attempted to disentangle the mission and purpose of hospice – a fairly new development – from the even newer question of physician assisted suicide. Their research revealed several areas of tension in practice and in the ways in which hospices describe the relationship of their mission to the reality of legal assisted suicide. In the end, it comes down to whether hospices see physician assisted suicide as complementary to their mission of providing end-of-life care, or at odds with it. The article concludes with a set of “deliberation questions” grouped according to stakeholder interest and designed to help hospices clarify their understanding of PAS and how their mission relates to it.

Even though their article was published over two years ago, we are summarizing it here because of the possibility that PAS may be legalized states other than Washington, Oregon, and now California, in the near future.² We realize that a short summary carries the risk of inaccurately or incompletely representing the results of their study, but we believe that this article is a very good attempt to help hospices to clarify how they see PAS, both for their own integrity and for the benefit of patients, families and staff. Following the summary, I will describe a number of ethical questions that their research raises.

Their research focuses on “how hospice programs have interpreted their philosophy and mission to accommodate patient requests and the extent to which they may incorporate the process of physician-assisted death as part of the responsibilities of hospice caregiving.”³ Their analysis includes setting a context for practices and policies of the hospitals in Washington state; presenting an overview of their theoretical framework; and focusing on four key issues.

They studied documentation from 33 hospices. Their initial analysis focused on nine key areas: 1) The background philosophy of hospice care; 2) the language used by the hospice to refer to patient requests for assistance in dying; 3) the policy or statement of position; 4) the values invoked by the hospice to support that position; 5) the practical processes used by a hospice upon receipt of a patient request; 6) the caregiving commitments of a hospice upon receiving a request; 7) the restrictions a hospice program placed on staff and volunteers; 8) the specific responsibilities or restrictions placed on staff regarding presence at a patient’s self-administration of medication; and 9) the independence or autonomy of the hospital relative to affiliation with hospitals and other organizations.

They distill these nine areas to four: 1) nomenclature used to describe the action legalized by the Washington Death with Dignity Act (WDDA); 2) values represented in the hospice policies; 3) position on staff presence; 4) position on staff participation.

Naming the Issue. Researchers found that Washington hospices use a variety of terms to describe what was legalized by the WDDA. These include physician assisted suicide, physician assisted death, physician

aid-in-dying, patient self-administration of a lethal medication, and hastening death. Most (10 out of 33) used “physician-assisted death.” This removes the stigma of “suicide,” but it is not entirely accurate, since physicians are rarely present when the patient takes the medication or dies as a result. So their “assistance” is remote. We will return to this question below.

Hospice Philosophy and Values. The authors’ analysis of documents identified 22 values specifically invoked by hospice documents. These included relief of pain and suffering, information disclosure, respect of conscientious refusal, compassionate care, non-abandonment, enhancing quality of life, respect for patient choice, respect for patient-physician relationship, and refraining from hastening death. These values were named with almost equal frequency. “Relief of pain and suffering” was explicitly named by 31 of the 33 hospices.

Dilemmas of Hospice Staff Presence. Despite their commitment to patient care and non-abandonment, 78% of hospices restrict their staff from being present, as a matter of policy, at time of self-administration of medication and during the time between ingestion and death. Only one hospice saw “supportive presence” even during administration of medication, to be part of their commitment not to abandon their patients.

The most important issue in my view is whether hospices see PAS as part of or complementary to their end-of-life care, or whether they see it as an alternative. Campbell and Black’s research identified four possible positions on this question. They describe the policies of 7 of 33 hospices as “opposition,” e.g., the hospice program “shall not offer, facilitate, participate in or provide an act that directly or indirectly leads to any person participating in the process of providing or facilitation.”

Eleven other hospices had what the authors describe as a “non-participation” approach, which they break down further into “procedural non-participation” (unwillingness to be part of the legal procedures leading to assisted suicide); and clinical non-participation (unwillingness to be part of the act of ingesting the medication).

A third category is “non-interference,” which means that assistance in dying is “a matter between patient and physician,” which places it outside of the scope of hospice care. This might be a variation on a “don’t ask, don’t tell” policy.

Finally, some hospices base their policies on the value of “respect for patient choice.” This means that they see providing information about all options, even self-administered medication, to be part of their mission to inform the patient even if they will not participate in or enable the act in any way.

Campbell and Black agree with Bruce Jennings that these variations demonstrate the “dynamics of an essential ethical tension”.⁴ They (and I) also agree with Jennings’ observation that physician assisted suicide represents a “defining moral choice” for hospice identity. They recommend that hospices must attend to this important issue by means of “reflection and discussion on the meanings and purposes of hospice care and understanding of fidelity and integrity to hospice values. The tool they present is designed to facilitate that reflection.

Ethical Issues

Campbell and Black describe their work as “reportorial, interpretative, thematic and coherentist.” They do not set out to provide a thorough moral analysis of various positions they report. I cannot do that in this brief article, either, but I would like to highlight what I see as some important ethical issues

raised by their investigation. These issues could, along with Campbell and Black's discernment tool, help hospices clarify their assumptions and their policies.

Terminology

Words matter. It is clear from the variety of terms used to describe the act by which a patient ends his or her life that there is some willingness to adopt different terminology in order to remove the stigma or actually redefine the act in a more socially or morally acceptable way.⁵ While "aid-in-dying," "self-administration of a lethal medication" and "hastening death" all sound more neutral, I believe that they obscure the fact that what is at issue is a patient's conscious, free decision to end her own life. We have always considered this to be suicide, and we have always maintained that it is immoral to the extent that it is a free, conscious act. We no longer deny suicide victims a funeral or burial in consecrated ground. This is an acknowledgement that we can never know the patient's state of mind at the time of the suicide. There is always the chance that the patient's moral freedom was limited by illness, depression or some other factor. But we still see suicide as objectively immoral.

The role of the physician is also at issue. Some hospices have opted for "self-administration" rather than "physician assisted" language, which appears to put the moral burden on the patient rather than the physician. Although the physician's "assistance" is remote, it is nonetheless real and formal, because the patient could not end his own life without the physician's active participation. Even if the physician is not physically present when the patient ingests the medication, he shares in the patient's intention to some extent. I believe we should keep the language of "physician assisted" to make it clear that the physician is not just a vending machine, but rather an informed moral agent who must accept some of the

responsibility for the patient's death. I also wonder whether it is ethical for a physician to supply the means for such an act, and then fail to be present when it takes place.

Killing, Letting Die and (unintentionally) Hastening Death

Another gray area is whether there is a meaningful moral difference between unintentionally hastening death by increasing doses of painkillers and actually taking steps to end a patient's life. As long as we have known that morphine can suppress respiration and possibly hasten death, we have analyzed it in terms of the principle of double effect. The intended effect is the relief of pain. We do not want or intend to hasten the death of the patient, but we can foresee that this might occur. In my view we should take care to assure that "hastening death" as an unintended side effect does not become confused with intentional attempts to bring about the patient's death.

Moral Complicity

Most of the policies analyzed by Campbell and White indicate sensitivity to the fact that the presence or participation of staff members in assisted suicide may involve unacceptable moral complicity or create moral distress for the caregiver. This is true for individual caregivers as well as for the hospice itself. Catholic hospices should therefore make it clear in their policies and in patient and family orientation that patients may not ingest medication while in a hospice facility. If they choose this route, they place themselves outside of the mission of the hospice and must check out to return home.

Moral complicity extends to statements about "respect for patient choice." How far can a staff member go in telling a patient about an option for assisted suicide without promoting or appearing to promote it? Perhaps it is acceptable to mention assisted suicide

only if the idea is introduced to make it clear that it is not part of hospice care.

Integrity of the Hospice Mission

Hospices have been struggling for greater acceptance for many years. It would be a shame if now, when hospice is becoming better known and more widely accepted, hospices obscure or confuse their missions by ambivalence about assisted suicide.

Acknowledging the possibility of assisted suicide in a hospice would be an admission that we cannot help you die well, but we can help you die.

We believe that death is the doorway to the ultimate purpose for which God created us. It is, as one author described it, an “adventure in Christ.”⁶ At least for Catholic hospices, it should be crystal clear that hospice is an effective *alternative* to assisted suicide, one that makes assisted suicide unnecessary. In our view, hospice is a clinical, psychological, social and spiritual program to help patients prepare for death and to achieve a “happy death,” one free from anxiety and pain and which occurs in the midst of a caring community.⁷

¹ Courtney S. Campbell and Margaret A. Black, “Dignity, Death and Dilemmas: A Study of Washington Hospices and Physician Assisted Death.” *J Pain and Symptom Mgmt.* 49(January 2014): 137-153.

<http://dx.doi.org/10.1016/j.jpainsymman.2013.02.024>.

² A summary of the status of “death with dignity” acts in all states, plus summaries of legislation in states that have approved it, is available at

<http://euthanasia.procon.org/view.resource.php?resourceID=000132> (accessed 3/29/2016).

³ *Ibid.*, 139.

⁴ Bruce Jennings, “Unreconcilable Differences? *Hastings Center Report* 41(2011): 4-5.

⁵ Campbell and Black make a similar claim when they note their conviction that “how the practice [of physician assisted suicide] is perceived and interpreted, as displayed by the language phrasing, is not value free but presupposes

value assumptions that inescapably influence moral assessments and policy positions...” (141).

⁶ Benedict Ashley, Jean deBlois, Kevin O’Rourke, *Health Care Ethics: A Theological Analysis*, 5th edition (Washington: Georgetown University Press, 2006): 166.

⁷ See Philippe Aries, *The Hour of Our Death* (Oxford, 1981) in which he discusses the persistence of the idea of a “tame death,” which is close and familiar. He contrasts this with the “wild death” that is isolated and out of control. Daniel Sulmasy makes a similar distinction in his book *The Rebirth of the Clinic*, in which he cites the unintended effects of clinical medicine after the Enlightenment.