

*Dignity, Death, and Dilemma: A Study of Washington Hospices and Physician-Assisted Death*

*Courtney S. Campbell, Oregon State University; Margaret A. Black, Einstein College of Medicine*

The extensive literature in biomedical ethics on physician-assisted death has represented the debate to involve three parties with significant interests. First, there are arguments regarding the legitimacy of terminally patients seeking to exercise an expanded right of self-determination. Furthermore, questions have been posed regarding the compatibility of a patient request for physician-assisted death with the professional ethics of medicine and of pharmacy, and of the ethics of individual practitioners who may or may not collaborate with this request for a prescription to end the patient's life. Third, discussion has address the role of the state, which requires assurance in public policy of both patient decision-making capacity and professional accountability to warrant rescinding paternalistic laws that prohibit or restrict patient rights at the end-of-life.

While these broader themes are a necessary part of this discussion, limiting moral assessment to the interest of these three constituencies neglects intermediate communities for end-of-life caregiving, including the moral commitments and practices of hospice care. This is a very problematic oversight since in the two states that initiated physician-assisted death as a legalized caregiving reality, the vast majority of terminally ill patients who end their life with physician-assistance are enrolled in hospice programs. Nearly 90% of patients who have used Oregon's ground-breaking "Death with Dignity Act" from 1998-2011 (n=522/596), and over 96% of patients in 2011 (n=59/61), were under hospice care.<sup>1</sup> Similarly, in the first three years (2009-11) of physician-assisted death in Washington State, 81% of patients who received and used a physician's prescription to end their life (n=127/157) were hospice patients.<sup>2</sup>

Although both Oregon and Washington have state-wide hospice programs, the enrollment of hospice patients who may make a request for assisted death from a physician's prescription can in part be attributed to the passage of the "death with dignity" statutes in these two states. For example, the

primary patient rights organization that facilitates arrangements for physician-assisted death, Compassion and Choices, refers terminally ill patients to hospice programs as a first resort for end-of-life caregiving. For some patients, clearly, their decisions about end-of-life care can encompass both the caring practices of hospice and palliation as well as an opportunity to receive information and make requests about assisted death. However, such requests can present difficult and defining questions about the purposes and scope of hospice as well as practical complexities for hospice programs and their staff, as illustrated in the following examples:

#### EXAMPLE 1

*A 61 year-old patient with a diagnosis of end-stage multiple sclerosis was referred to hospice care following a recent hospitalization. The patient has no family and is entirely dependent on caregiving staff for basic functions. Following his hospitalization, the patient vocalized a request for “death with dignity” to his primary physician, but his physician exercised his legal right to refuse to participate. The hospice program then contacts the state-wide patient advocacy organization to assist the patient in finding participating physicians, but the advocacy organization is unwilling to assist, citing concerns that the physical dependency of the patient would make him unable to self-administer the medication as required by law.*

*Following a consultation between the hospice executive director and head social worker, a decision is made that, although the hospice program understands itself and public represents itself as “neutral” on participating in patient requests under the law, since the patient does not have a family advocate, nor the assistance of the patient rights organization, the hospice will assume an advocacy role for the patient in trying to locate physicians who will participate in the patient’s request to receive a prescribed medication to end his life.*

## EXAMPLE 2

*A terminally ill patient is referred to a hospice program for end-of-life care. Following discussion with her hospice caregivers and attending physician, she requests a prescription to end her life in accord with the state Death with Dignity Act. The patient is informed that the hospice respects the patient's legal right to pursue the process to obtain a medication from her physician, and that regardless, the hospice will continue to provide customary hospice care. However, as stipulated by the hospice's policy on involvement with patient requests for a medication to end life, the hospice will not have a staff person or nurse in attendance when the patient takes the medication. The patient understands and respects this policy. She then requests that the hospice team not inform her family members of her intent to use the Death with Dignity process, as is the patient's right under the law. The patient is divorced from her husband, who has strong religious commitments, and she believes that disclosure of her request to family members would generate substantial disruption in an already difficult family situation.*

*The patient receives a prescription for the medication, obtains it, and takes the medication attended by persons from the patient rights advocacy organization, Compassion & Choices, and dies without any complications. Following customary practice, Compassion and Choices then contacts the hospice program requesting a hospice staff member to visit the home to provide confirmation of death, and a hospice nurse arrives shortly thereafter to confirm death.*

*Soon after the hospice nurse arrives, the patient's daughter comes for a visit to her mother and is aghast to find her mother deceased. The daughter feels betrayed by the hospice and questions the nurse, asking "why didn't you tell us about this?" The nurse confides to her staff supervisor that she experienced moral distress over this circumstance, and felt that she had deceived the family and the daughter.*

### EXAMPLE 3

*A hospice nurse developed a professionally meaningful caring relationship with a cancer patient and his family over three months. The nurse is aware that her patient has requested a prescription from his attending physician to end his life as permitted by state law. As this prospect approaches, the patient asks the nurse if she will be present when the patient takes the medication (the law requires the patient to self-administer the medication).*

*The nurse has a professional but deep commitment to this patient, and has expressed to other caregivers how meaningful it has been to be a “companion on the journey” of her patient. In considering the patient’s request for her presence, however, the nurse is cognizant of the written policy of her hospice program, which affirms the right of hospice patients to choose any legal end-of-life option, but prohibits any hospice staff or volunteer from attending the dying of a patient using the Death with Dignity law. This prohibition encompasses presence both when the patient self-administers the medication and in the duration between self-administration and the time of patient death. Hospice staff are permitted to provide post-death care to patient and family as per any other death under hospice care.*

*The nurse is conscientiously committed to the purposes of hospice care and views hospice nursing as her “calling” or vocation. However, the request of her patient generates a moral conflict for her regarding responsibilities of devoted patient care, non-abandonment of her patient, and fidelity to her hospice program and its policies. The nurse decides she will attend the patient’s use of the medication “as a friend, not as a nurse.”*

In the wake of recent legalization of physician-assisted death statutes<sup>3</sup> and the significant proportion of terminally ill patients who use the state laws in Oregon and Washington while enrolled in hospice care, we have been interested in whether and 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. This essay examines the policies developed by hospice programs in Washington State to outline their caregiving responsibilities and restrictions when a terminally ill patient makes an inquiry or request regarding physician-assistance in ending their life. Our analysis will proceed by (1) setting a context for the policies and practices of individual hospices in Washington State by situating them relative to the discussion of national hospice organizations; (2) present an overview of our theoretical framework for analysis and interpretation of policy materials for Washington hospices; (3) focus on four specific issues – the controversy over language regarding the act legalized by the state Death with Dignity statute, the values that underlie and support the positions of individual hospice programs; the issue of presence of hospice staff when a prescription is taken by a hospice patient (per example 3); and, our own analysis of the extent of participation or non-participation of individual hospice programs – that emerge from the policy documents; and, (4) conclude with a framework of questions, embedded in the Washington hospice statements, that we propose can be useful for other hospice programs who will face question in the foreseeable future.

We approach our analysis with the assumption that, as noted above, the conventional approach to the question of legalized physician-assisted in bioethics literature and in liberal political philosophy has missed the issue of how the requirements of a new law are carried out by the primary caregiving institution, hospice care, for terminally ill patients who have recourse to the law. Our analysis will highlight ethical values, commitments, and conflicts embedded in these policies and seek to assess their *coherence* with respect to the hospice philosophy of care. We do not seek here to give a normative assessment of the death with dignity statutes. Rather, our interest is that, given the legalization of physician-assisted death, how do hospice programs portray and represent their commitments and involvement with patient requests made in accordance with the statute. In this respect, our approach in

this paper is best understood as reportorial, interpretative, thematic and coherentist. We describe our core questions further below (see pp. 10-12).

### *Background*

The discussion of the role of hospice in the practice of physician-assisted death does not occur in a philosophical, moral, or professional vacuum. Many hospice policies make reference to the values of “hospice philosophy,” which we contend are constituted, at a minimum, by the following interpretations and commitments: (a) a view of dying as a natural process; (b) a moral precept to neither prolong nor hasten dying (which reflect the bioethical principle of non-harm); (c) compassionate provision of methods to relieve pain (the principle of beneficence); (d) patient (and family) participation in decision-making (the principle of autonomy); and (e) fidelity to patient welfare that includes non-abandonment of both patients and families (the principles of beneficence and non-maleficence).

Such commitments are reflected not only in policies of local hospices, but in statements of national hospice organizations as well, including the National Hospice & Palliative Care Organization (NHPCO), the Hospice and Palliative Nurses Association (HPNA), and the American Academy of Hospice and Palliative Medicine (AAHPM). In 2005, NHPCO issued a “Commentary and Resolution on Physician-Assisted Suicide” that was shaped by two guiding concepts, the value of life and access to high quality end-of-life care. Hospice care and palliative measures were portrayed as effective in almost all circumstances to relieve pain and distress without resorting to “purposefully hastening death.” Even though NHPCO represented hospice and palliative care as an “alternative to PAS” and affirmed a position that it “does not support the legalization of physician assisted suicide,” the resolution commentary advocated a commitment to organizational participation in policy discourse directed at improving and promoting patient comfort and dignity and that bestows the “highest regard for patient choice and self-determination.”<sup>4</sup>

The NHPCO position is largely echoed by a 2011 position statement adopted by the Hospice and Palliative Nurses Association. The HPNA position affirmed opposition to legalization of physician-assisted suicide, but also stated that nurses were to be “vigilant advocates for humane and ethical care for the alleviation of suffering and for the non-abandonment of patients.”<sup>5</sup>

In 2007, the AAHPM approved a position statement on physician-assisted death (rather than physician-assisted suicide, as in the NHPCO or HPNA resolutions). The AAHPM substantially agreed that quality medical and palliative care, complemented by the caregiving resources and skills of hospice staff, can “relieve most suffering near the end of life.” However, the statement recognizes that on rare occasions “severe suffering persists,” which may generate a patient request for physician-assisted death through a lethal medication to “end otherwise intolerable suffering.” The Academy recommended that practitioners seek to address the many-fold sources of suffering at life’s end “without hastening death,” and to engage in caregiving that “reduce[s] any perceived need for PAD.” Nonetheless, the AAHPM ultimately differed from the NHPCO on its policy position, articulating a position of “studied neutrality” on the legalization of physician-assisted death,<sup>6</sup> adopting a viewpoint first advanced by physicians Timothy Quill and Christine Cassel.<sup>7</sup>

These overlapping but contrasting perspectives from national hospice organizations are of interest on their own merits. Here, we wish to offer a very brief analysis on two issues that help illuminate the policies, responsibilities, and restrictions developed by hospice programs in Washington State. A first question is clearly that of differing nomenclature. The AAHPM critiques the language of “physician assisted suicide” as “emotionally charged” and contends that “physician assisted death” better “captures the essence of the process in a more accurately descriptive fashion” than does the alternative phrasing. As discussed subsequently, individual hospices in Washington offer six differing forms of concepts to describe the action, none of which are free of value assumptions. The legalizing

statutes in both Oregon and Washington are entitled “The Death with Dignity Act” and the language used to describe what happens when a terminally ill patient requests a lethal medication of their physician is “end [the patient’s] life in a humane and dignified manner” (with the Washington statute clarifying that the patient is to “self-administer” the medication). The language of humanity and dignity is no less emotionally charged and value-laden than that of “assisted suicide.” Neither statute “authorize[s] lethal injection, mercy killing, or active euthanasia,” and “ending life in a human and dignified manner” under the provisions of the statute does not legally constitute “suicide, assisted suicide, mercy killing or homicide...”<sup>8</sup> The diversity of language represented in national hospice policies and in individual policies in Washington State (as described below) reflects public and ethical discourse generally and is not unique to the hospice context. Our claim here is simply that how the practice is perceived and interpreted, as displayed the language phrasing, is not value-free but presupposes value assumptions that inescapably influence moral assessments and policy positions developed by hospice programs.<sup>9</sup> In our analysis, we will use the language of “physician-assisted death” because our conviction is that it best leaves the ethical questions open, allowing for discussion and rational argumentation to be presented without linguistic pre-judgment.

A second issue embedded in the statements of the national organizations is an understanding that hospice and palliative care is appropriately directed towards measures to relieve symptoms and ensure quality, dignity, and comfort at life’s end. In short, they primarily reflect the ethical responsibility of beneficence and the virtue of compassion. They do not, however, adequately grasp the principal political and legal justification for physician assistance in the death of a terminally ill patient, namely, that it is a matter of “rights,” or respect for the patient’s autonomy and self-determination. The authorizing legal statutes in both states make no reference to the experience of severe pain or intolerable suffering as an indication for a patient to make a request for physician-assisted death, but rely entirely on the entitlement due a patient in respect of their personal dignity. A patient rights



framework provides the primary moral structure in the context of hospice caregiving in Washington (and Oregon), with secondary appeals to virtues of compassion and principles of beneficence and justice. We contend that there can be complementarity rather than inconsistency between a philosophical justification for assisted death based on compassion and beneficence and a legal justification based on beneficence. Relative to the statements of the national hospice organizations, the attitudes and policies of Washington hospice programs are more attentive to the patient rights construct of terminally ill patients, and it is to those attitudes and policies that we now turn.

### *A Framework for Interpretation*

In the winter and spring of 2012, we collaborated with the Washington State Hospice and Palliative Care Organization (WSHPCO) in an effort to collect documents, including policies, position statements, and staff education materials, from affiliated hospice programs on their philosophy and praxis on physician-assisted death. WSHPCO does not itself have any position on the question, in contrast to the Oregon Hospice Association, which portrays hospice care and physician-assisted death as mutually complementary approaches to a commonly shared goal of respecting patient rights and self-determination in end-of-life care.<sup>10</sup>

We contacted thirty-five hospice programs affiliated with WSHPCO, requesting any program documents pertaining to their philosophy, policy, or procedures when a hospice patient makes a request for information or assistance pertaining to physician-assisted death under the Washington Death with Dignity Act. We received thirty documents representing thirty-three of the thirty-five hospice programs. One hospice program replied but indicated they would not share any of their program information, and one program did not reply despite repeated inquiries. Thus, the response rate of Washington hospice programs was 94.3%.

We made an initial analysis of the policy documents using a set of considerations developed in a prior study of Oregon hospices and physician-assisted death.<sup>11</sup> We sought to understand and interpret

the documents with respect to (a) the background philosophy of hospice care or mission statement of a hospice program; (b) the language or nomenclature the hospice program used to refer to patient requests for a prescribed medication from a physician with the intent to end life; (c) the policy or statement of position articulated by a hospice program with respect to their participation or involvement with the process and/or act of physician-assisted death; (d) the values invoked by the hospice to support their policy or position; (e) the practical processes a hospice initiates either upon receipt of an inquiry from a patient for information about the law or a request from a patient to pursue physician-assisted death; (f) the caregiving commitments a hospice assumes upon receipt of an inquiry or request; (g) the restrictions a hospice program placed on caregiving staff and volunteers with respect to involvement in a patient's inquiry or request; (h) the specific responsibilities or restrictions on hospice staff concerning presence at a patient's self-administration of the medication, and (i) the independence or autonomy of the hospice relative to affiliations with other caregiving organizations, such as hospitals or corporate agencies. While not every Washington hospice program has articulated policies addressing each of these considerations, these nine considerations reflected general fidelity to the information in the documents and provided a conceptual framework for basic understanding and analysis.

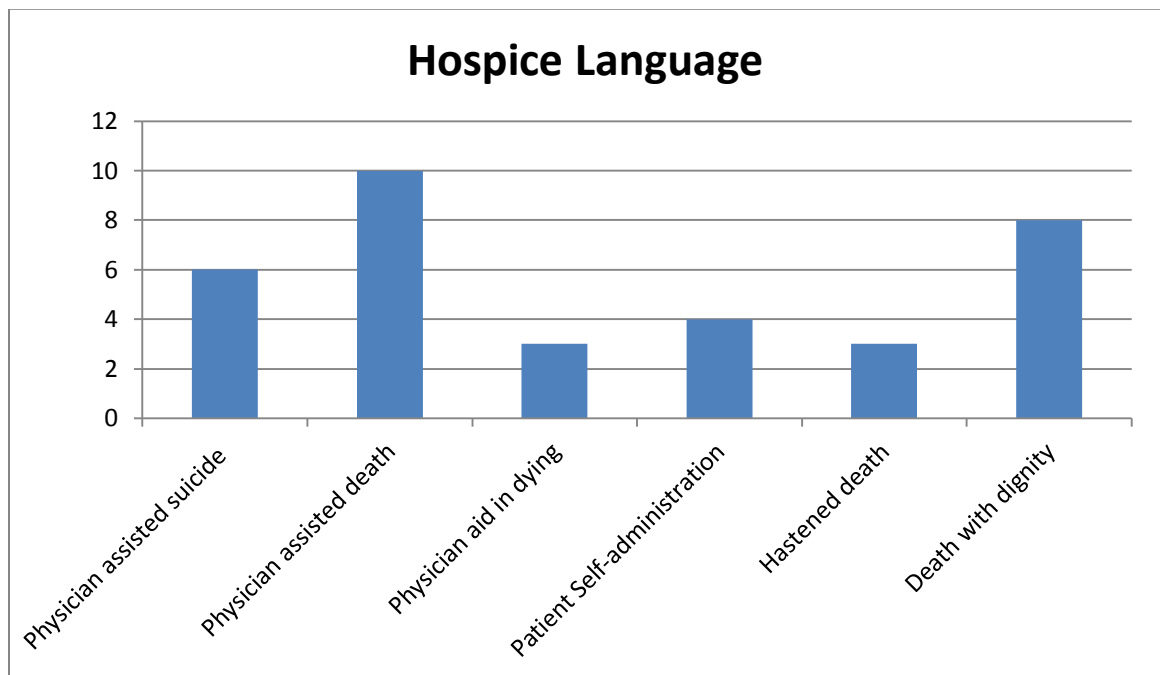
In this essay, we wish to focus on four of our nine questions for comparison and contrast in these policies: (1) What nomenclature describes the action legalized by the WDDA?; (2) What values are represented in the hospice policies? (3) What positions do Washington hospices affirm on the specific question of staff presence to a patient or family at the time of medication ingestion?, and (4) What general policy positions do Washington hospices articulate regarding program or staff participation in the WDDA? We focus on these four questions because they were addressed in all policies. Our analysis relies on common themes and patterns in the thirty documents that illustrate coherence between hospice values and positions as well as invite opportunities for contrast and comparison.

### *Naming the Issue*

As noted previously, national hospice organizations disagree about what language best conveys what occurs when a terminally ill patient makes a request of a physician for a prescription to end life. It is thus not only the different values embedded in hospice mission but also the values embedded in the language used to refer to this recently legalized medical practice that shapes the positions of hospice programs. Alternatively, in some instances, the selection of language can reflect previously-adopted positions.<sup>12</sup>

Our analysis of Washington hospice policies displayed six different ways that the process or action legalized by the Washington Death with Dignity Act is portrayed: physician-assisted suicide, physician-assisted death, physician aid-in-dying, patient self-administration of a lethal medication, hastening death, and the statutory title of death with dignity. The number of hospices using a particular description is illustrated below in Table 1.

TABLE 1



This presents a very different linguistic landscape among Washington hospices compared to their counterparts in Oregon.<sup>13</sup> While the concept of “suicide” was used in 53% of the Oregon hospice policies (as well as in the NHPCO resolution), that proportion falls to 16% (n = 6) in the policies of Washington hospices. Perhaps not surprisingly, all of the hospices that use the language of physician-assistance in suicide are programs with religious affiliations and values. Meanwhile, 39% (n = 13) of the Washington programs use the language of physician-assisted death or physician aid-in-dying in their policies (in contrast to 22% in Oregon), a perspective more consonant with the AAHPM statement.

The language of physician assistance in death or physician aid-in-dying is not by itself indicative of the position of a given hospice on the extent of their involvement with patients who use the legal process to make a request for a prescription to end life. Such phraseology does remove the moral and emotional pre-judgment of the patient’s decision-making embedded in the terminology of physician-assisted suicide, and entails that the position of a particular hospice is primarily conditioned by the background understanding of hospice mission and its supporting values.

Despite important differences in how to describe the outcome of a request (suicide or death or dying), it is significant that these three phrases have in common the designation of “physician” as the primary professional resource for carrying out such actions. An attending physician outside the hospice setting undertakes an assessment of decision-making capacity, oversees an informed decision or consent process, and writes the prescription for the patient. Thus, despite the substantial proportion of patients using the law who are enrolled in hospice care, hospice programs do not understand themselves or their staff to be “assisting” in suicide or death. The designation of a “physician” as the primary professional resource for patients allows hospice programs to maintain fidelity to the norm that “*hospice* neither prolongs nor *hastens* dying” (our emphasis). In short, even though most patients who use the Death with Dignity rights are enrolled in hospice, hospice programs want to stress that this is a “physician” directed process, not “hospice assisted” death.

All hospice programs express aspirations that their patients experience dignity in their dying, as defined by the patient's own values, although the actual dying process makes realizing this aspiration extremely difficult. The 24% (n=8) of Washington hospices that use the phrasing of "Death with Dignity" in their policies have simply made a pragmatic choice to appropriate the statutory language into their policy statements. They are not making a philosophical claim that patients who make use of the legal process to end their life will experience a qualitatively distinctive (and better) kind of death than other hospice patients who die from their underlying disease process. However, since the statute does permit patients to make a request for medication to end life "in a humane and dignified manner," no Washington hospice program that uses the statutory language in their policy statement affirms a policy posture of opposition or refraining from participation.

Two phrases used by some Washington hospice policies – patient self-administration of medication (12%, n=4) and hastening death (9%, n=3) – were not represented in the policies of Oregon hospice programs and that we have not encountered in other hospice (as contrasted with ethics) literature on this issue. These phrases are significant in their own ways within a setting of hospice care. The language of patient self-administration is appropriated from the Washington statute, and shifts the focus from a process directed by a physician to a specific act initiated and carried out by a patient. On one hand, this is compatible with the hospice commitment that the patient (and family), not a professional, are in control of the dying process. However, precisely because the act of self-administration is performed by a patient in hospice care, it can pose very wrenching questions for hospice programs about both patient physical capacities to self-administer (as illustrated in our first vignette) and whether staff are allowed to attend the patient's act or subsequent dying (as illustrated in our second vignette).

The language of "hastening death" is used by a small cluster of hospice programs with identical policies. While the phrase is descriptively accurate about what typically happens when a patient ingests

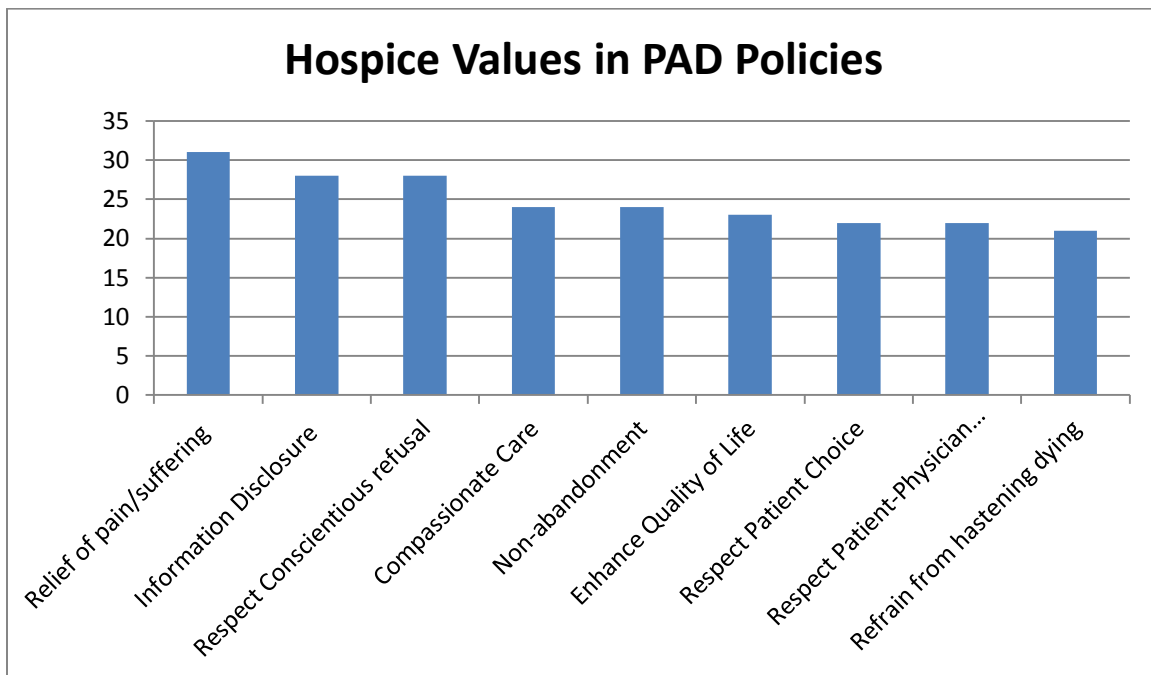
the medication, describing the process in this manner appears to compromise a central hospice precept that dying or death is not to be hastened. It thus raises a broader question about an evolving hospice identity and integrity in which, in contrast to historical tradition and practice, hospice programs are willing to incorporate practices that hasten death. Insofar as several hospices in both Oregon and Washington have policies with respect to palliative sedation, in which pain relief is the primary goal even if death is hastened as a secondary consequence, it may be that some hospice programs could legitimately claim that issue has already been resolved, and physician-assisted death is the moral equivalent for hospice of palliative sedation.

The plurality of ways that hospice policies describe patient requests for medication to end life is important to acknowledge; certainly, in many policies, there are values on the scope and mission of hospice care embedded in these concepts. We contend that hospice and public discourse can best be advanced on this issue by reliance on a shared concept – physician-assisted death – that leaves the ethical questions open, permitting discussion and rational argumentation to prevail rather than linguistic pre-judgment.

### *Hospice Philosophy and Values*

The policies of hospice programs manifest different values within as well as between hospices reflect practical caregiving issues presented for programs and staff by patients who make an inquiry or request about physician-assisted death. Our analysis identified twenty-two values explicitly invoked in the hospice policies and documents. We focus here on those values that were most prevalent (mentioned in at least 50% of the documents) in the thirty-three policies as a whole; at the same time, we acknowledge that the absence of a value from a policy statement does not mean it is not embodied in caregiving practices or procedures. Table 2 presents a tabulation of the most prevalent values in the policies of Washington hospices pertaining to program and staff responsibilities regarding physician-assisted death.

TABLE 2



The prevalence of these values reflects wide-spread commitment among Washington hospices to assure a quality end-of-life experience for hospice patients and families and promote informed decision-making as consonant with respect for patient dignity. Some commonly-cited values address both characteristics and concerns of hospice caregivers; thus, hospice staff are to embody the virtue of compassion in their care, but also may conscientiously refuse to provide care if that would create a personal moral conflict. In every circumstance in which personal, moral or ethical values are cited as a basis for a caregiver to request they withdraw from being the responsible caregiver for a patient that makes a request, another staff member must be available to assure continuity of care and avoid violating the hospice value of non-abandonment. Two traditional tenets of hospice philosophy – non-abandonment and refraining from “hastening death” -- remain prevalent values but create their own complications. As described more fully below, non-abandonment must be re-interpreted when hospice staff are asked to be present at the patient’s ingestion of medication or at the death. The restriction on

hastened death, meanwhile, is less frequently invoked than considerations of promoting informed choice or respecting and honoring patient decisions. As noted below, the restriction on not hastening death may be less ethically compelling given that many programs have separate policies addressing palliative sedation, although we do not have empirical information on how many programs also have policies on palliative sedation.

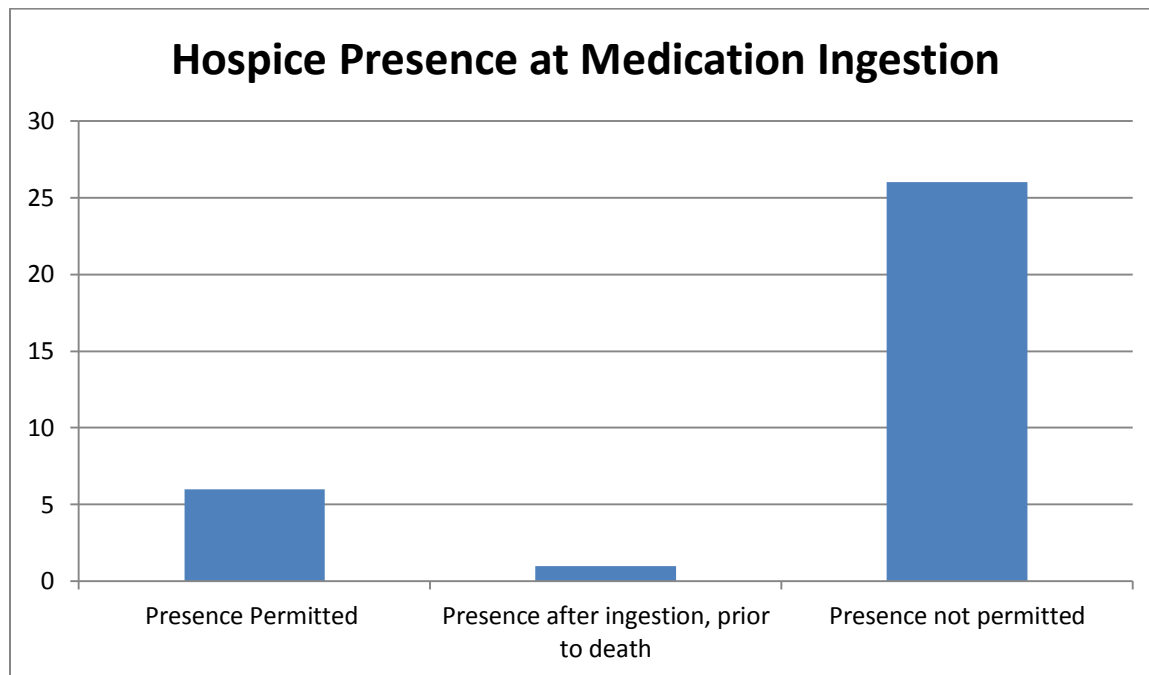
The above table is comprehensive but not exhaustive of all values invoked in the policy documents. We believe that most of the twenty-two values we identified correspond with the nine presented as most prevalent, but it is also important to recognize that the primary values that inform the positions of religiously-affiliated hospice programs are not among the most prevalent. These values include respect for the sacredness of human life, respect for the integrity of the healing professions, and an understanding of persons as possessing “stewardship” rather than autonomy over their lives. Such values shape non-participation positions of these hospices in patient decisions and requests for physician-assisted death, and some may have resonance among the general populace even if not among other hospice programs.

### *The Dilemma of Hospice Staff Presence*

The Washington statute provides latitude for professional caregivers regarding whether they will “be present when a qualified patient takes the prescribed medication to end his or her life in a humane and dignified manner.”<sup>14</sup> It is permissible action, but not a legal obligation. Should it however be a hospice obligation, given the prominence of the commitment to non-abandonment in hospice philosophy and in the specific hospice policies? Of any caregiving practice, Washington hospices display the greatest diversity of positions on the issue of staff presence when patient self-administration occurs. As illustrated in Table 3, nearly 78% (n=26) of Washington hospices have as a matter of policy restricted their staff from being present at the time of patient self-administration of the medication, as well as the duration between ingestion and death.



TABLE 3



The policies themselves are relatively silent as to the rationale for these decisions among individual hospice programs. Those hospices that permit staff presence invoke the value of non-abandonment or the importance of continuity of care. Thus, one policy indicates that staff presence upon patient request should be understood as comparable to “any other end of life visit in which symptom management and comfort are the focus,” while a program coordinator whose hospice permits clinical staff presence affirmed (in subsequent correspondence) that “supportive presence is more consistent with our commitment to not abandon our patients and families.”

Given that non-abandonment is a core philosophical value of hospice, we contend there is a responsibility of transparency and moral justification for those hospice programs that do not permit presence until a post-mortem visit, when staff would customarily pronounce death, notify the patient’s physician, and provide emotional or other forms of assistance, including bereavement care, to the family. The claims offered to justify restrictions on staff presence appeal primarily to symbolic concerns about perception, although one policy presented a very clear instrumentalist or pragmatic rationale.

Some policies indicate that “witnessing” a patient’s action of medication ingestion is “outside the scope of hospice practice.” This position disputes the rationale for presence offered above that presence is part of the continuum of end of life caring rendered by hospice. Other policies and hospice directors maintain that presence is the equivalent of “condoning the practice” and thus compromises hospice integrity. Still other program directors maintained (in subsequent conversation) that, as family members are not always informed or supportive of the choice of their loved one (see vignettes 1,2), hospice does not want to be perceived as “taking sides” in a family dispute.

Finally, one program indicated that since the law requires self-administration of the medication, and hospice is by law and well as hospice policy not to be involved in medication administration, refraining from being present allows hospice staff to avoid all prospect of assistance with the medication. This may be particularly compelling in circumstances where the patient experiences complications with the medication (e.g., when the patient aspirates the medication), and some further medical treatment is needed by the patient for death to occur. In this context, the restriction on hospice staff presence serves as a further check against physician-assisted death becoming hospice-assisted death.

Regardless of the position on presence at self-administration, all hospices may confront an issue of what measures can be undertaken should a hospice staff member undertake a visit to a patient, either unaware that the patient has ingested the medication but has not died, and/or is experiencing complications from the medication. It is customarily the case that someone is attending the patient during this circumstance, either the attending physician (25% of reported cases), or much more frequently (63%), a volunteer from Compassion and Choices. However, 21% (n=7) of Washington hospices have addressed the options for hospice staff in situations when a home visit is made and inadvertently is present during or immediately after self-administration.

Among these hospice programs, there is a convergence of views that a hospice staff member is to provide “appropriate quality hospice care” or “professional services,” with the provision that such care or services do not assist in hastening death. The specific practices of care are not delineated in the policies, other than one program that permits its personnel to provide “comfort measures,” including symptom management to address the patient’s pain or nausea. For the other six programs, however, additional medication is not to be provided because of the prospect of hastening death. There are also differences among these programs as to whether “quality hospice care” permits calling other resources. Some hospices do not permit staff to call emergency services like 911, or permit staff to make such a call only with a documented request from the patient or family; the rationale presumably is that emergency personnel will treat the situation as a suicide and seek to resuscitate their person. Still other programs indicate hospice staff can present the family with two options: a call to 911, or to contact the prescribing physician to provide direction about action to be taken. However, these programs stipulate that the calls must be made by the family, not by hospice staff. Hospice staff may also contact a hospice supervisor for “direction and support,” but none of the policies that address this circumstance affirm a responsibility of the staff member to contact the attending or prescribing physician.

In these policies, there is a clear differentiation of roles between the role of hospice and the role of the physician; hospice provides care appropriate to hospice, the physician has the responsibility to address medical issues from self-administration including complications. We contend that this circumstance should be considered by all hospice policies and have a recommendation to this effect in our concluding framework for hospice deliberation.

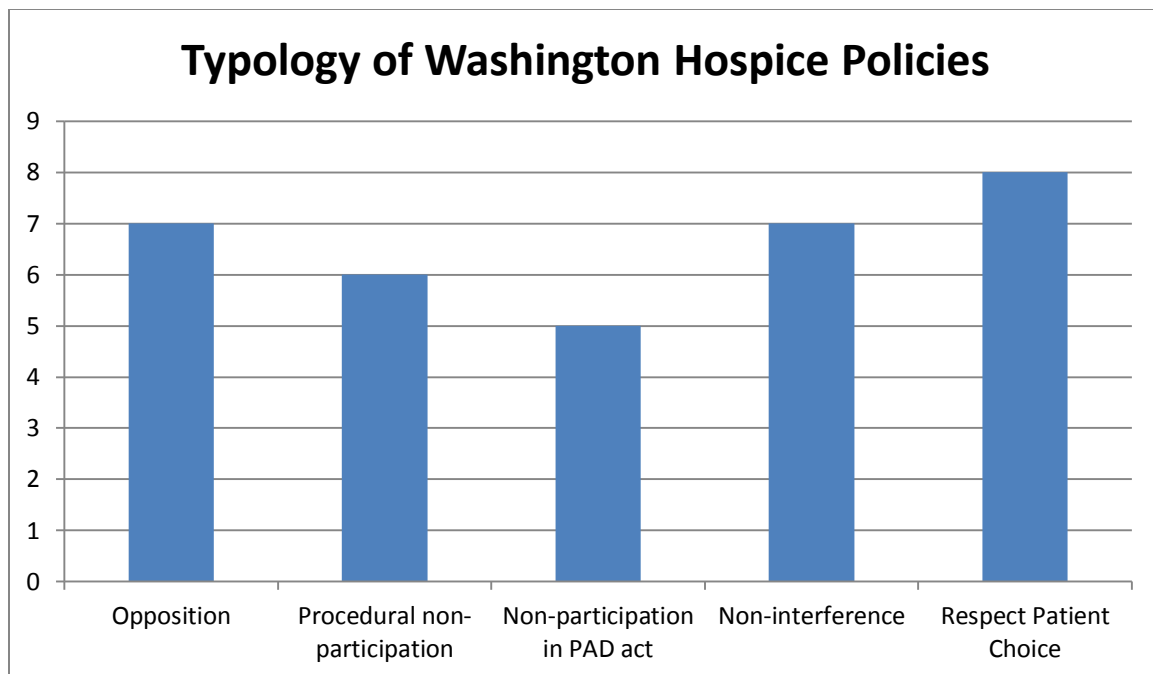
#### *Hospice Positions: Alternative or Complement?*

The Washington Death with Dignity Act makes no mention of hospice, other than stating that patients must be informed by their attending physician that hospice is a “feasible alternative” to a request for life-ending medication.<sup>15</sup> Some policies prioritize the values of “hospice philosophy”

identified previously (page 6) to support the conception of hospice as an “alternative” (and perhaps a preferable alternative) to physician-assisted death in end-of-life care. Still other hospice programs, relying on a different interpretation and prioritization of primary values, tend to portray hospice as less an alternative and more as a comprehensive program of end-of-life care whose philosophy and values are ultimately compatible with advocacy of patient rights of self-determination, including a right to request physician-assisted death. These differing conceptions of the role of hospice relative to the law are displayed in the policy statements of individual hospice programs. Again, we reiterate our approach here attempts to discern how these hospice positions cohere with hospice values and philosophy.

Our analysis here relies on self-representations of the policy in the documents, assessment of the coherence of the policy position with the values embedded in the policy, restrictions imposed by the policy on staff involvement, and occasional follow-up clarification with hospice program directors (as well as a subsequent presentation to WSHPCO). We identified five different positions through which hospice programs negotiate their responsibilities for care of hospice patients who make inquiries or requests regarding a prescription to end their life. These positions are visually portrayed in Table 4 below, following which we provide a brief summation of the primary policy categories.

Table 4



**Opposition** – We use the category of “opposition” to describe the policies of seven hospice programs (21%) who characterize their position on legalized physician-assisted death as “non-cooperating,” “opposed” and/or “non-involvement.” Hospice staff in these programs are restricted or “prohibited” from participating in a patient request. While six of these programs have religious affiliations, perhaps the most all-encompassing statement of restriction is expressed by a community-based hospice with no religious affiliation. This policy informs both staff and patients that the 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 facilitating a person requesting medication to end his or her life in a manner contemplated under the Washington Death with Dignity Act ...”

Although each of these hospices is willing to provide hospice care for patients who express interest in physician-assisted death, such hospices clearly understand their care to be an alternative to physician-assisted death, and moreover an alternative that has very strong moral warrants, based on the value of human life, commitments to care for vulnerable persons, and the integrity of the healing professions. The caregiving boundaries that hospice staff must not cross include (a) providing

information regarding the law or legal process; (b) making direct referrals to participating physicians or referrals to patient rights organizations; (c) securing an informed decision by the patient, including assistance in the legally required oral and written requests, such as by serving as a witness to the requests; (d) provision of any assistance on behalf of the patient to obtain or administer the medication; and, (e) staff presence when the patient takes the medication. Should a patient in these programs express intent to choose physician-assisted death, they are informed or reminded of the hospice policy and restrictions. Nonetheless, these programs do not contemplate any circumstances of patient discharge; indeed, since PAD patients can continue to receive customary hospice care, it is perhaps not surprising that these programs develop the most substantive instructions for hospice staff should a staff member inadvertently visit a patient's home prior to or when the patient has initiated self-administration of the medication but has not yet died. In such circumstances, staff may be required to remove themselves from the premises until the patient has died, or to provide "appropriate quality hospice care" or "professional services that do not assist in death." Upon notification of death, hospice staff can initiate customary post-mortem and bereavement care.

**Non-participation** – Eleven hospice programs (33%) represent their position as "non-participation," but there are sufficient nuances in the statements of these hospice programs to warrant a distinction in levels of non-participation. Some programs emphasize non-participation in the *process* required by the law for the patient to obtain the medication, while others refrain from participation in circumstances pertinent to the specific *action* of the patient to end their life.

Six hospices (18%) that affirm what we designate as a posture of *procedural non-participation* are concerned to refrain from staff or hospice involvement with the *process* outlined by the Washington statute for a patient to *receive* life-ending medication. The restrictions in these policies both overlap with and extend the restraints on forms of involvement identified in the preceding category, such as refraining from providing information about the law, including distributing brochures prepared by

patient rights organizations; initiating contact or notification of the patient's attending physician; witnessing necessary legal documents; assistance in patient deliberation; or providing various forms of assistance with the prescribed medication, including information about how to dispose of unused medications. These restrictions are primarily directed at the processes by which patients make an informed decision about requesting medication to end life, which are deemed the responsibility of others besides hospice programs or staff. The primary justificatory claim for the stance of non-participation is that involvement in the process includes activities that are "outside the scope of hospice practice." This does not mean these hospices will cease to provide care for such patients; such programs affirm a commitment to the value of non-abandonment. Patients who do express interest in physician-assisted death may be referred to their attending physician, the Washington State Department of Health or (more infrequently) the patient rights organization Compassion and Choices in Dying, to obtain the information and initiate the legal processes.

The second cluster of self-identifying non-participating programs (n=5, 15%) directs their posture of non-participation not at the background legal procedure, but rather at staff involvement with the *act* of patient ingestion of the medication. These hospices not only permit but require greater staff involvement regarding certain procedural aspects of the patient's choice. Their policies insist that staff respond to patient inquiries with "openness and compassion," or put another way, with transparency about information and a non-judgmental attitude; some policies even stipulate an "obligation" for staff to engage in open discussion with the patient about concerns regarding the dying process as well as "the meaning behind the patient's questions." These programs do not see their role as displacing the patient's physician as the ultimate resource for patient inquiries (and legally certifying the decision), but they do stress hospice responsibilities in educating patients regarding end-of-life alternatives, including advance directives, hospice and palliative care, as well as the Washington statute, through both conversation and distribution of relevant publications.

Why then do such programs represent themselves as “non-participating” in their policies? They understand non-participation to mean “not assisting a patient to end their life.” While the law requires self-administration of the medication by the patient -- and no Washington hospice policy crosses this legal boundary -- once the patient has made an informed decision, these hospices draw a line on participating in such practices as preparing the medication so it can be consumed; presence or witness to the patient’s ingesting or dying; or patient needs for post-ingestion caring, especially in the event of complications (see previous discussion). However, though the hospice as a *program* may have a self-understanding of non-participation, that does not restrict hospice *staff* from substantive engagement with patients on matters of education, conversation, and exploration of the meaning of dying for the patient for either (or both) of the following purposes, “helping the patient make informed decisions” or ensuring a “safe and comfortable dying” as defined by the patient.

**Non-interference:** We have constructed a category of “non-interference” comprised of seven hospices (21%) whose unifying theme is that decision-making about physician-assisted death “is a matter between the patient and his or her physician,” rather than a role encompassing hospice responsibilities or staff. In one respect, all Washington hospices could be placed in this category in that no program indicates they would interfere to prevent a qualified patient to exercise of his or her legal right to physician-assisted death. Nonetheless, these particular hospices emphasize the sufficiency of the physician-patient relationship for deliberation regarding physician-assisted death, and that this relationship and this deliberative process are in morally important respects beyond the purview of the hospice scope of care. However, these programs come to this conclusion for quite different reasons.

Four programs (12%) develop their policy position with respect to *values* they affirm in caring for patients who make a request for a lethal medication under the Washington statute, while refraining from either using the language of “non-participation” in some form or indicating support for patient self-determination. The primary values invoked by these programs are compassion in response to patient



inquiries or requests and “aggressive” management of pain symptoms. These programs also echo the emphasis of the NHPCO resolution on advocacy for access to hospice care. The caregiving procedures of these programs allow staff the latitude for conscientious refusal to provide care for a patient who has requested physician-assisted death when they experience a “moral or ethical conflict,” but assure continuity of care for patients. They recognize the physician as the primary professional resource for initiating the legal process, and restrict staff presence when the patient ingests the medication.

A second group of hospice programs (n=3, 9%) could be understood as a variation of the non-participation posture, although they modify that position through a provision that they do not “actively” or “directly” participate in the law. These programs do not elaborate on what might constitute passive or indirect participation; however, what is decisive to us is how these programs represent their policy to patients, namely, that in response to patient inquiries, the hospice is to assume a “neutral” role in information disclosure, and should the patient choose to proceed with a request for physician-assisted death, they will be “informed of the role of hospice regarding participation in the law, that is, this is an issue between patient and physician.” Whether the substantive content of patient-physician conversations are ultimately outside the realm of hospice care seems to be of less significance for these programs than that the patient has a opportunity to explore their interests with a physician (rather than with hospice staff), even while the patient continues to receive quality care from staff.

These programs appeal explicitly in “hospice philosophy” tenets to ground their policies and practical procedures, primarily the naturalness of dying and the commitments of hospice to both not hastening death and to non-abandonment of patients and their families. However, despite the commitment to non-abandonment, none of these hospices permits staff members to be present at self-administration and each recognizes the legitimacy of conscientious refusals of staff members to provide care for patients who choose physician-assisted death, provided that another staff member delivers hospice care.

**Respect for Patient Choice:** A final posture is represented by those hospices that frame their policy position in terms of “respect” or “support” of patient choice (n=8, 24%). These programs emphasize a programmatic responsibility to ensure that patients have full information about options in end-of-life care, including the option of patient self-administration allowed under the Washington statute, and that should a patient make a decision to pursue physician-assisted death, the hospice responsibility encompasses respecting, honoring, and supporting that choice as consonant with the patient’s dignity.

While all Washington hospice programs emphasize a degree of commitment to promote patient choices, these hospices may be differentiated from the previous four categories in that (a) they do not self-identify as a “non-participating” program; (b) they recognize the sufficiency of patient choice rather than situating the issue as outside the domain of hospice care and something to be determined by the patient and attending physician; (c) they do not interpret patient requests as reflecting some inadequacy in caregiving that could be remedied for almost all hospice patients by quality hospice care, but instead view patient choice as a basic legal right of terminally ill patients with sound decision-making capacity; and, (d) while honoring patient choice, they contend their support of patient self-determination should not be understood as “promoting” or “advocating” physician-assisted death as a preferable end-of-life option. The responsibility of hospice to patients who choose physician assisted-death is rather framed as “providing support and dignity in the best interest of the patient.” Further, within this posture of general advocacy of patient choice in end-of-life care, (e) seven of the eight programs permit staff to be present when the patient self-administers the medication (one program allows presence post-ingestion but pre-death). This difference from other programs reflect an understanding that hospice should attend deaths from patient self-administration with “care similar to any death that occurs in [the] hospice,” and that that the practice of presence is more consonant with the value of non-abandonment.

Two policies in this category of respect for choice articulate differences worthy of attention. These policies are unique among Washington hospices in referring to the “ethical principles” presented by the NHPCO Code of Ethics – autonomy, beneficence, conscientious objection, nonmaleficence, and justice – as grounding for their positions.<sup>16</sup> Their affirmation of support for patient rights with respect to end-of-life decision-making thereby appeals to moral principles inclusive of hospice values, but these principles are drawn from the broader context of bioethics discourse.<sup>17</sup> However, these programs also express the aspiration that in providing hospice care with “compassion, dignity, and respect,” the concerns of terminally persons will be “alleviated ... sufficiently that the *smallest possible number of people would choose this new option*” (our emphasis). These policies assert that quality hospice care at its best can make a difference in how a patient experiences their dying: honoring and supporting patient wishes is an affirmation of patient dignity, while caregiving mediated by compassion and quality may diminish the frequency of patient choices for physician-assisted death. That is, these policies present a distinction between respecting patient choice and assuming that assisted death is a necessary outcome of the exercise of that choice. In keeping with this approach, no limits are placed on staff involvement in conversations or information provided to patients so long as staff members assume a “nonjudgmental and neutral” role regarding physician-assisted death.

For programs that affirm respect and support for patient choices, hospice care and physician-assisted death are best understood as complementary paths in end-of-life care rather than mutually exclusive options. This does not mean that these hospices necessarily engage in unique practical caregiving interventions. While they articulate substantive responsibilities for hospice staff in providing information useful to the patient’s decision-making process and in referring patients to physicians or programs that can best facilitate the process, they also respect the boundaries the law draws concerning provision of the medication (a matter for physicians and pharmacists) and with patient self-administration of the medication, even if hospice staff are present. In addition, for many of these

programs, the important question is not whether a patient may choose physician-assisted death, but where the self-administration occurs; restrictions or guidelines on location are specified in several policies. Nonetheless, what is distinctive about these programs is their vision of hospice care and physician-assisted death as complementary, based on compatibility of formative values.

### *Conclusion: Hospice Integrity*

The question of the scope of hospice caregiving and what it means to express fidelity or integrity to its practical ramifications has been discussed extensively by others<sup>18</sup> and is beyond the purview of our interests in this essay. The hospice responsibility for informed choice and the commitment to high quality end-of-life care are complementary expressions of the identity and scope of hospice practice. Yet, physician-assisted death presents one circumstance in which they are not easily reconciled and instead create what Bruce Jennings has described as “the dynamics of an essential ethical tension” in hospice philosophy. Jennings contends that legalized physician-assisted death presents a defining moral choice for hospice identity because “legalization [of PAD] would liberate dying people from what hospice had been teaching could be a meaningful and valuable time of life. On the other hand, a major part of that quality of living while dying that hospice champions is autonomy, respect, and dignity. How could hospice stand against that?”<sup>19</sup> In the policies of Washington hospice programs, this ethical tension is displayed through different nomenclature, values, responsibilities for presence, and program policies. As represented above, hospice programs that explicitly prioritize informed patient choices as a core feature of hospice care tend to impose fewer restrictions on hospice staff involvement with the patient’s deliberative process and on requests for end-of-life staff presence without believing they have compromised the distinctive mission of hospice care, while those programs that represent their perspective as opposition, non-participation, or even non-interference tend to manifest different views of the meaning of hospice, and develop different responsibilities and restrictions on staff involvement.

We concur with Jennings that legalized physician-assisted death presents a defining question that requires reflection and discussion on the meanings and purposes of hospice care and understandings of fidelity and integrity to hospice values. This process of examination should be carried out by national hospice organizations, state programs, and individual hospices. As part of this process, it is important for hospice staff to engage in personal deliberation and introspection. Indeed, a few Washington policies stipulate that hospice caregivers have a “personal responsibility” to reflect critically on their own values, their views about the Washington law, and commitments of caring for patients who request physician-assisted death.

To facilitate a deliberative process, we present as our conclusion a comprehensive set of questions that, in our assessment, were presupposed in the Washington hospice policy documents for a given statement of position or practice to appear as part of a policy. That is, given the program information we received, we engaged in reflection on *what question had to have been asked for a precept or practice to appear in a policy statement*. We have organized these questions for deliberation primarily around the kinds of interactions a hospice program or hospice staff might have with various stakeholders in a patient’s decision, including the patient; other members of the hospice team; other health care professionals or institutions; and community resources or organizations beyond the hospice program.

We do not mean to imply that any particular hospice program addressed all of these issues. This informs our proposal for ongoing deliberation, examination, clarification and policy development and refinement. Our intent is to present a framework for a comprehensive hospice policy on physician-assisted death to assist this process at the national, state, local, and personal levels of moral discussion.

## FRAMEWORK FOR HOSPICE DELIBERATION

Hospice Procedure	Framing Questions
Hospice Philosophy	<p>What is the mission of hospice (or the agency)?</p> <p>What makes hospice distinctive?</p> <p>What values support this mission or purpose?</p> <p>What actions would fall outside the realm of hospice care?</p>
Hospice Policy Formulation	<p>What is the policy of a hospice on participation in the Death with Dignity Act?</p> <p>What is the purpose and who is the audience for the policy?</p> <p>What language will the policy use to describe the event? (e.g., physician-assisted suicide, physician-assisted death, death with dignity, physician aid-in-dying, self-administration of lethal medication)</p> <p>How was/will the policy be composed, and who did/will compose it?</p> <p>What will be the rationale for the policy (e.g., religious tradition, professional ethic, hospital policy, hospice mission)?</p>
Patient Access to Hospice Care	<p>Will patients receive customary hospice services irrespective of their interests in a medication to end life?</p> <p>Will the patient be informed by hospice of all their legal rights and options in end-of-life care?</p> <p>Will the hospice notify the patient of the hospice policy regarding their participation in the Act? If so, when and how?</p>
Patient Inquiries about Physician-Assisted Death	<p>What responsibilities does a hospice have to a patient who makes an inquiry?</p> <p>If a patient has questions about the Act, will they be referred to their primary care physician for information?</p> <p>If a patient has questions about their legal options, will they be given contact information about community or state resources that can answer their questions?</p> <p>Will the hospice provide information (written or verbal) about the law?</p> <p>Will the hospice provide educational brochures about the law prepared by non-hospice organizations?</p>
Staff-Patient Conversations	<p>Will members of the hospice staff have a conversation with the patient about their inquiry or request?</p> <p>How should hospice staff understand their role in such a conversation (e.g., neutral, advocates)?</p> <p>Will hospice staff seek to identify physical, emotional, social, or religious factors that may contribute to the patient's request?</p> <p>Will patients be informed that their wishes will be communicated to members of the hospice team?</p>
Specific Patient Requests	<p>Will hospice staff be permitted to facilitate the process of informed consent or informed request?</p> <p>Are hospice staff permitted to act as witnesses of the patient's request?</p> <p>What responsibilities, if any, do staff have (or must refrain from) with regards to the prescribed medication?</p> <p>Will hospice staff provide information to the patient or caregivers regarding the safe disposal of medications?</p> <p>If requested, will hospice staff be permitted to be present when a patient's self-administers the medication?</p>
Hospice Staff Decisions	<p>Will staff be encouraged to consider their own perspectives on whether they can provide care to a patient who makes a request?</p> <p>Will a patient inquiry or request be communicated to members of the hospice IDG Team?</p> <p>Will staff have a conversation about the plan of care in light of a patient inquiry or request?</p> <p>Will the hospice documentation the patient's request and subsequent conversations in a patient's record?</p> <p>What responsibilities do staff have if they wish to discontinue caring for a patient who requests use of the Death with Dignity Act?</p> <p>Will hospice staff be permitted to be present post-ingestion, but prior to death?</p> <p>What are hospice staff permitted to do in the event of complications from self-administration?</p> <p>What are staff responsibilities post-death to the family?</p>
Hospice-Provider Relationships	<p>What is the role of the hospice relative to the attending physician?</p> <p>Will the hospice notify the attending physician of a patient's interest in a lethal medication?</p> <p>Will a hospice leave the decision-making process to be worked out between physician and patient?</p> <p>Will the hospice refer a patient to other providers in the community?</p> <p>Will the hospice provide information about pharmacies that will dispense the prescribed medications?</p>
Resources	<p>Will the hospice refer a patient with questions about the law to the Washington State website?</p> <p>Will the hospice refer a patient with questions to patients' rights advocates such as Compassion and Choices?</p>

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