

# HOSPICE AND PHYSICIAN-ASSISTED DEATH

## *Collaboration, Compliance, and Complicity*

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Although the overwhelming majority of terminally ill patients in Oregon who seek a physician's aid in dying are enrolled in hospice programs, hospices do not take a major role in this practice. An examination of fifty-five Oregon hospices reveals that both legal and moral questions prevent hospices from collaborating fully with physician-assisted death.

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*Case One: A hospice patient with a diagnosis of terminal cancer indicates in conversation with a trusted hospice spiritual care counselor that he has questions about and interest in Oregon's Death with Dignity Act, which allows terminal patients to request a prescription for medication to end life from their attending physician. The hospice for whom the counselor works has a written policy stipulating that the hospice does not actively participate in requests for physician-assisted death made in conformity with the act. The counselor considers what steps she may take with the information the patient has confided in her.*

*Case Two: A hospice nurse develops a professionally meaningful, caring relationship with a cancer patient*

*and her family over three months. The nurse is aware that her patient has requested a prescription to end her life under Oregon law; as this prospect approaches, the patient asks the nurse if she will be present when the patient takes the medication. While the nurse has a deep commitment to this patient, the written policy of her hospice prohibits any hospice staff or volunteer from attending the dying of a patient using the law. The nurse wonders how she can balance caring for her patient, fidelity to hospice values (like not abandoning patients and families), and support for her particular hospice program's policies.*

According to data collected by the Oregon Department of Human Services, 88.2 percent of terminally ill patients who from 1998 to 2009 used the state's Death with Dignity law to end their life were enrolled in hospice care.<sup>1</sup> This figure climbs to 95.1 percent in the two most

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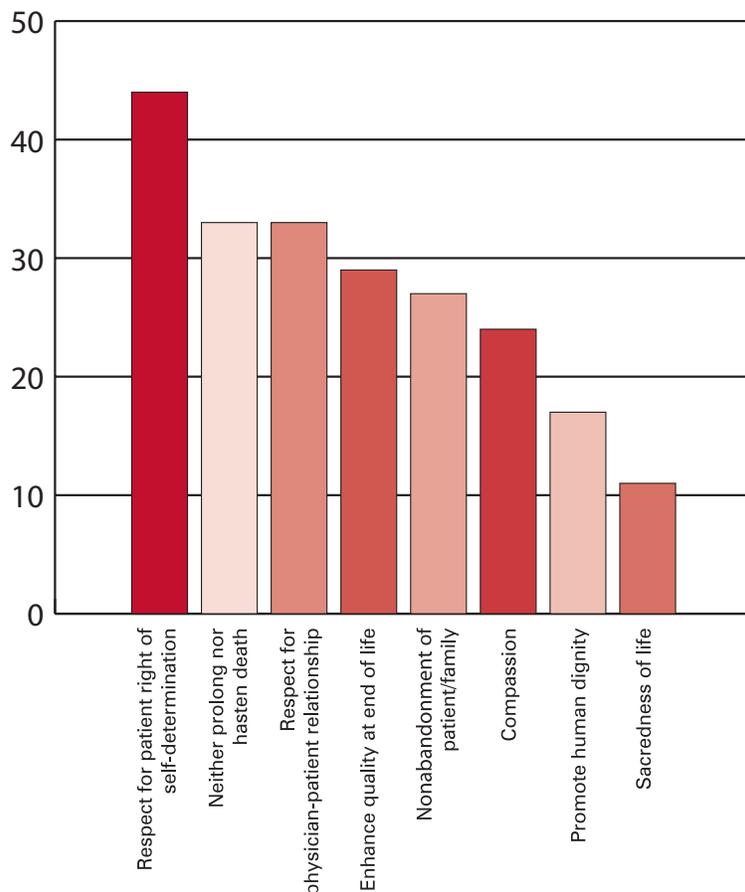
recent years (2008–2009) of available data.<sup>2</sup> Two significant points are suggested by these ratios. First, terminally ill patients seeking physician-assisted death are receiving high-quality palliative care. Patients do not exercise their legal right to choose physician-assisted death because they are unable to obtain good symptom management. Second, hospice programs are regarded as an important societal mechanism to assure that physician-assisted death is practiced responsibly.<sup>3</sup> The most prominent patient rights advocacy organization, Compassion and Choices of Oregon, makes referrals to hospice a primary feature of its patient care counseling.<sup>4</sup>

The Oregon Hospice Association tells its professional and patient constituencies that hospice is “uniquely qualified to address the needs of the dying” and that terminally ill patients need not feel compelled “to choose between hospice and physician aid-in-dying.”<sup>5</sup> Moreover, the OHA contends that “a hospice should never deny a person its services because he or she has asked a doctor for a prescription.” But the OHA’s view is more an aspiration than a reality. The vast majority of Oregon hospice programs set programmatic, professional, and moral boundaries to their involvement in physician-assisted deaths, and many of them do not participate in most or all features of implementing physician-assisted death under the Oregon law. Indeed, most Oregon hospice programs treat deaths attributable to physician-prescribed medications differently than other deaths that they attend.

During 2009, in order to assess the extent to which Oregon hospice programs participate in physician-assisted death, we requested policy statements, program guidelines, and staff education materials that had been developed by sixty-four hospice programs affiliated with the Oregon Hospice Association to address patient inquiries about the Death with Dignity Act. We received forty documents representing fifty-six programs. However, one hospice stated its

policy was “in development.” Thus, our analysis concentrates on responses from fifty-five programs, or 86 percent of state-affiliated hospice programs. Our examination of these documents suggests that individual hospice programs generally assume a minor role in the decision-making process of patients who exercise their rights to physician-assisted death—a role largely confined to providing information about the law in a “neutral” manner. Moreover, hospices claim they will not assist with providing the medications necessary to hasten a patient’s death. This limited role indicates that questions of legal compliance and moral complicity inhibit hospice collaboration with patients seeking physician-assisted death.

**Figure 1.**  
**Hospice Values on Physician-Assisted Death**  
Number of Hospices N = 56



### Hospice Philosophy and Values

The policies and guidelines of Oregon hospices on physician-assisted death reflect an attempt to be faithful to the historically formative values of hospice care, including the philosophy that death is a natural continuation of the human life span, that the dignity of each dying patient should be affirmed, that the quality of a patient’s remaining life should be promoted through the highest level of caring commitment, and that hospices should evince a distinctive devotion to symptom and pain management.<sup>6</sup> In our study, these constitutive values tend to apply broadly to both the nonreligious hospice programs that responded to our request (there were forty-five such programs),

as well as hospices with religious affiliations (of which there were eleven). However, with the emergence of physician-assisted death as a legal end-of-life option, specific hospice programs may give greater priority to particular values, or they may specify their practical content in a distinctive fashion. The most commonly articulated values, as reported by individual hospices in their policies on physician-assisted death, are set out in Figure 1.

The ethical challenges that physician-assisted death poses to hospice programs are revealed by some tensions embedded in these core values. These challenges include:

1. reconciling the commitment not to hasten death with patient requests for physician assistance in obtaining medication to hasten death;
2. reconciling the commitment not to abandon patients and their families with the general posture of avoiding involvement with medication or assistance regarding the act of medication ingestion; and
3. reconciling the commitment to respect the integrity of the physician-patient relationship for patients who request physician-assisted death with the interdisciplinary and holistic mode of hospice care that involves nurses, social workers, spiritual care counselors, and others.

These foundational values provide certain directions for offering care to hospice patients seeking physician-assisted death. For example, the value of nonabandonment implies certain enduring commitments to patients and families. They do not resolve the issue of which caregiving procedures a hospice should adopt in response to a patient inquiry, nor do they generate a statement of general hospice policy with respect to participation in physician-assisted death. Rather, the policies of a majority of hospice

programs contain nuanced wording that indicates patient requests for physician-assisted death create tensions respecting involvement, legal compliance, and an intent to avoid moral complicity.

For example, some hospice programs' positions use language that proscribes "direct" or "active" participation by the hospice or its staff in physician-assisted death (as reflected in case one above). This phrasing leaves open the possibility that the hospice would participate in some passive or indirect way, while implying that direct or active participation would be contrary to hospice integrity. Still other hospices contend that physician-assisted death, whatever its legal status in society, is not compatible with the values adopted by the hospice; these programs have opted to oppose participation, supported by a clause in the statute that stipulates hospices have "no legal requirement to participate" (ORS 127.885 s.4.01). This suggests that some values distinctive to that hospice are embedded in the position; many hospice programs opposed to participation have a religious affiliation within Roman Catholic or other religious caregiving traditions. Still other hospices affirm that respect for patient choices to "direct" or "control" their care is the core component of hospice philosophy.

Figure 2 displays eight different ways that Oregon hospices self-reported their programmatic positions on physician-assisted death. While each of the fifty-five hospices represented in it certainly claim to be in compliance with the provisions of the legal statute, they nonetheless describe their position on the practice of physician-assisted death in quite different ways. This diversity in positions on hospice participation in Oregon's Death with Dignity Act cannot be explained solely by explicit statements of values or philosophy; it also shows a divergence in caregiving practices.

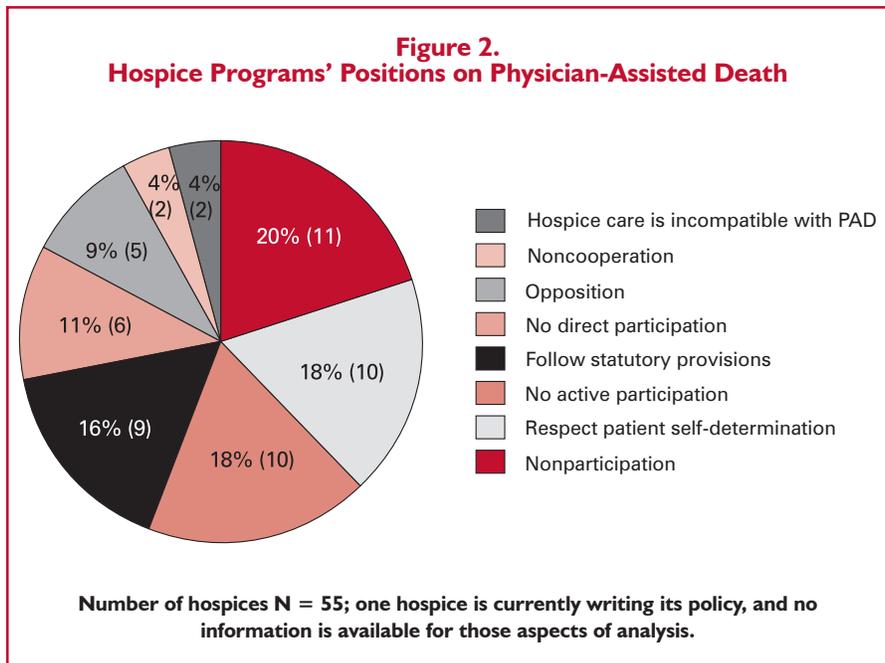
## Boundaries of Hospice Care

While all Oregon hospice programs promise "standard hospice services" to all patients, our analysis of why Oregon hospices present eight general kinds of positions on physician-assisted death reveals differences over four of five principal caregiving considerations. Hospice programs (1) use different language to describe the act of a hospice patient obtaining a physician's prescription to end life; (2) provide different degrees of information in response to patients' questions or requests regarding physician-assisted death; (3) engage in different levels of notifying the patient's attending physician who will write the prescription (a physician invariably different from the hospice medical director); and (4) present different views of whether hospice staff may be present prior to and during the ingestion of life-ending medication. With respect to a fifth caregiving consideration—whether to provide the patient with the prescribed medication or assist in the patient's act of self-administration—Oregon hospice programs have invariably adopted a posture of nonparticipation. The differences that emerge in analysis of these caregiving considerations suggest that physician-assisted death confronts hospice programs not only with the ethical challenge of reconciling conflicts on constitutive values, but perhaps more fundamentally poses an issue of defining boundaries about the identity and moral integrity of "hospice" and "hospice care." We discuss each of these caregiving considerations in turn, and then provide examples or models of how particular hospice programs address these issues in their program positions and caregiving procedures.

*Language and moral complicity.* The terminology used to describe what occurs when a physician prescribes a lethal dose of medication for a terminally ill patient who subsequently self-administers the medication to hasten death has been a perennially divisive issue. Field testing

prior to passage of the Oregon law in 1994 disclosed that when the process was described as “suicide” or as a form of “euthanasia,” popular support declined by 10 to 12 percent.<sup>7</sup> Advocates for the law subsequently adopted the concept of “death with dignity,” stipulating that a patient’s attending physician was the gatekeeper to the prescription that allows a terminally ill patient to “end his or her life in a humane and dignified manner” (ORS 127.805 s.2.01).

Hospice programs have not been immune from either this linguistic controversy or the normative value assessment embedded in the choice of terms. Oregon hospices endorse no uniform concept in their program policies, but the majority—twenty-nine of the fifty-five hospices represented in our analysis—retain the language of “assisted suicide.” Twelve use “physician-assisted death,” and fourteen simply refer to the “Death with Dignity Act.” All hospice programs that have opted not to participate in the Oregon law, as well as most that describe themselves as opposed to “active” or “direct” participation, use the language of “physician-assisted suicide” in their program policies. If a hospice frames the life-ending process as a “suicide,” then questions of participation become very problematic because the hospice would appear to be complicit in an act that the hospice movement has opposed from its historical origins. By contrast, hospice programs that use the language of “physician-assisted death” or “death with dignity” are generally more inclined to some degree of collaboration with both patients and physicians, even though (as indicated below) other boundaries may be drawn to ensure that the process remains one of “physician-assisted” death rather than “hospice-assisted” death. The relationship of language and program position thus displays a significant issue of identity and moral integrity within which issues of moral complicity are embedded. Such issues are, however, assumed rather than discussed by the hospice programs.



*Informed choice and hospice neutrality.* As illustrated by case one, hospice staff and hospice programs can face difficult questions when a patient inquires about or requests physician-assisted death. Some hospices that have policies of nonparticipation do not provide information to patients; instead, they ask patients to respect their position. This approach remains the exception, however: most programs have decided, at a minimum, to provide information about the law and the qualifications stipulated by the law for obtaining medication. Providing basic information is construed as integral to the hospice commitment to help patients make informed decisions. Some hospice programs endorse a more substantive dialogue, in which staff may “explore” with the patient the patient’s interest in physician-assisted death. The “exploration” also provides a procedural safeguard, in that it allows hospice staff to ensure that the patient’s interest has not been fostered by inadequate hospice care.

Nonetheless, issues of moral integrity and complicity are embedded in two ways in policies on information disclosure. First, some hospices designate specific staff personnel (typically, social workers) to provide

the requested information. (Prior studies have indicated that hospice social workers and nurses are most frequently involved in information provision.<sup>8</sup>) Second, many programs stipulate that staff members who provide information (or discuss it) must adhere to a posture of “neutrality.” The goal is that the patient will make an informed choice, in consultation with family members, according to the patient’s values, not those of hospice staff. Staff members are to neither persuade nor dissuade patients from opting for physician-assisted death. The concept of “neutrality” thus is the communication analog to hospice’s philosophical commitment that death is to be neither hastened nor postponed; moreover, it allows those hospice programs concerned about complicity in suicide to minimize their role and influence in a patient’s choice.

*Physician notification and collaboration.* Consistent with the goal of promoting not only informed but also voluntary choice, the legal statute requires that only a terminally ill patient can initiate a request to the attending physician for assistance with death. It is entirely possible that this process can bypass a hospice program altogether—a prospect explicitly

recognized by nineteen (about 35 percent) of the represented hospices in policy statements acknowledging that the decision about physician-assisted death is “a matter between the patient and his or her physician” (this view seems implicit in all policies except those from the cluster of nonparticipating hospice programs). While some patients prefer that hospice not be involved as a matter of personal privacy, hospice programs may participate by encouraging contact with an attending physician or organization that provides education and counseling for patients.

With the exception of programs that have opted for noncooperation or nonparticipation, a substantial majority of hospice programs express a willingness to refer patients who have inquired about physician-assisted death to the patient’s attending physician. Furthermore, hospice programs that allow staff to have exploratory conversations with patients about their interest in physician-assisted death are also willing to refer a patient to education and advocacy organizations; the most common referral prospect in the hospice policies is Compassion and Choices of Oregon. In addition, the patient will commonly be informed that the hospice interdisciplinary team involved in his or her care will be notified of the inquiry or interest in physician-assisted death, although this does not necessarily entail any modification in the plan of care.

The issue that seems to cause notification, referral, and internal reporting to evolve morally into collaboration and complicity emerges when a patient requests that a hospice oversee or coordinate the visits or referrals to an attending physician or education organization. Nine hospice programs express the view that facilitating a patient-physician meeting or making a patient referral violates their policies. The remaining hospice programs are silent on this matter, which means there is no hospice with a policy explicitly stating that it will oversee the patient and

attending physician’s discussion of physician-assisted death. This boundary is itself consistent with the principle of respecting the integrity of the physician-patient relationship, but as noted, it also reflects a concern to ensure the process remains physician-assisted, not hospice-assisted. The task of coordinating arrangements with a participating physician falls to the patient or his or her family; it may often be mediated by Compassion and Choices of Oregon.

*Nonabandonment and presence.* As illustrated by case two, one of the challenges for hospice programs is whether to allow staff members to be present when life-ending medication is ingested, in order to provide support for the patient and for family members. There is no legal requirement that any person—including any health care provider—be present when the patient takes the medication. State reporting indicates that during 2009, the prescribing physician was present just over 6 percent of the time when the medication was ingested. Between 2001 and 2009, a prescribing physician was present in just under 24 percent of cases; another provider besides the prescribing physician was present in 60 percent of the cases, and in approximately one in six cases (17.1 percent), no provider has been present.<sup>9</sup>

Some hospice staff express the view that the core value of nonabandonment entails that hospice policy should not only permit staff members to be present, upon the patient’s request, at ingestion, but that presence is mandatory for the hospice program (although the legal right of any particular staff member not to be present would be respected). Nonetheless, among the hospice programs represented in this analysis, very few have a policy allowing (not mandating) staff presence; thirty-one of the fifty-five represented in our analysis—including all those programs self-designated as nonparticipating or noncooperating—have stated prohibitions against staff presence. Eleven permit it, and twelve have no statement.

While the value of nonabandonment grounds the case for hospice staff presence, it is not clear from the programmatic statements of hospice philosophy or policy what particular value is so compromised by staff presence that it warrants prohibiting staff presence. The presence of a staff member does not itself violate the commitment not to hasten death; nor does prohibiting presence when a patient ingests life-ending medication mean that hospice care will cease, since virtually all hospices specifically indicate that they will provide postmortem bereavement support to the family—a form of care implicit in the promise of providing standard hospice services.

Hospice staff would typically attend the death of any other patient, if requested, as part of customary hospice care. Hence, for hospice programs that do not permit staff presence in cases of physician-assisted death, the question is how this kind of death is *morally and vocationally different* from any other kind of death that hospice attends. In two site visits, conversation with hospice staff revealed two principal issues of moral complicity associated with staff presence: First, hospice staff worry that being present at ingestion can create a public perception that hospice encourages or endorses physician-assisted death, or even that the hospice program may be responsible for ensuring that physician-assisted death happens without any complications. Hospice restrictions on staff presence are believed to maintain the moral neutrality or moral distance of hospice from direct participation in physician-assisted death, or at least to avoid creating a misleading perception that hospice condones physician-assisted death.

Second, in approximately one of every twenty physician-assisted deaths, a postingestion complication has occurred (primarily the patient regurgitates the medicine).<sup>10</sup> If a hospice care provider were present when the complication occurred, hospice staff claim, that person would feel

compelled to intervene and provide, for example, antinausea medication, so that the patient's dying would be free of further complications. However, in this scenario, the hospice staff member could plausibly be understood to have assisted in bringing about death, violating a hospice prohibition on assistance and potentially contravening the law. Thus, prohibiting staff presence at the time the patient ingests the medication avoids what could be a moral and legal compromise should the patient need assistance. Of course, it is also precisely in these kinds of circumstances that the hospice imperative to not abandon patients seems most compelling.

Even for hospice programs that permit staff to be present when a patient ingests medication, the boundaries of hospice care and avoiding moral complicity are important. Thus, whether a hospice staff member is making a routine visit to the patient, or is contacted by the patient or family member, or is already present at ingestion, if complications occur, the responsibility of the staff member is to render "appropriate quality hospice care." This includes attending to "human needs" regarding the patient's comfort and safety, including addressing bowel and bladder care, nausea, or spiritual care. The moral boundaries for staff are established in the few hospice documents that address caregiving when "complications arise" by first distinguishing "hospice care" from "physician assistance" in the dying process, and second, by identifying "human" needs that apply to all patients for comfort and safety, as contrasted with "medical needs" that specifically pertain to the patient's request for physician-assisted death, which are considered the domain of the prescribing physician.

It can also be claimed that, insofar as hospice programs generally acknowledge that the relationship between patient and attending physician is the primary context for negotiating the physician-assisted death process, it is ultimately the responsibility of the primary health care

professional to attend the ingestion and death. One hospice program specifically affirms that "it is the physician's responsibility to provide the patient with the requested support." The difficulty here is that if less than 25 percent of physician-assisted deaths have been attended by the primary physician, this is not a responsibility participating physicians have accepted.

### Prohibiting Assistance

We have discussed four hospice caregiving considerations concerning physician-assisted death—terminology, information disclosure, physician referral, and staff presence at ingestion—over which Oregon

the medication the patient will use to end his or her life and on staff assisting with the patient's self-administration.

Although the prohibition on assistance could be understood as a moral line drawn by hospice programs beyond which they cannot go without compromising their integrity and mission, the rationale for this prohibition is actually more complicated. For the few hospices who adopt a nonparticipatory posture on physician-assisted death in general, this prohibition is clearly compatible with other moral boundaries they have adopted. However, for the remaining hospice programs—that is, the majority of Oregon hospice programs—the prohibition on assistance, while

**The differences that emerge in how various hospice programs approach caregiving considerations suggest that physician-assisted death confronts them not only with the ethical challenge of reconciling conflicting values, but with the more basic challenge of defining the boundaries of hospice and hospice care.**

hospice programs diverge. By contrast, two policy matters seem to be universally affirmed by all hospice programs. The first is a promise to provide customary hospice care and services to all patients (although the discussion above makes clear that what constitutes customary care is disputed among hospice staff and between hospice programs). The second is prohibiting assistance regarding medications. Virtually every hospice policy document—including those that otherwise allow staff to participate to some degree in the process—contains a statement that reads: "Hospice X will not provide, pay for, deliver, administer, or assist with medications intended for [physician-assisted suicide/physician-assisted death]." Thus, hospice programs affirm restrictions on the organization and its staff assisting with securing

perhaps reflecting some moral sentiment grounded in the commitment not to hasten death, appears often to manifest accommodation of legal and practical realities.

In the first instance, in the documents sent us by many hospice programs, the prohibition on staff and programmatic assistance follows prefatory statements that recognize hospice patients can choose physician-assisted death as a legal end-of-life option and acknowledge that the decision to do so is ultimately determined within the relationship of patient and attending physician—a relationship distinct from that of the patient and the hospice care team. Put another way, the hospice prohibition on assistance presupposes the implementation of statutory provisions that effectively insulate hospice programs from the decision-making

process. Furthermore, since legally, the terminally ill patient must administer the medication him or herself, a sympathetic and compassionate hospice staff member cannot assist in the death of his or her patient without the risk of violating legal statutes against assisting suicide, mercy killing, active euthanasia, or homicide (ORS 127.880 s.3.14). The law also stipulates that it is the attending physician's responsibility either to dispense the medication directly or, with the patient's consent, to contact a pharmacist with a prescription that the pharmacist will dispense (ORS 127.815 s.3.01).

**If hospice staff do not disclose more than contact information for prescribing physicians, do not facilitate collaboration with them, and are not present at ingestion or death, then hospice enrollment cannot mean all patient care issues in this context are resolved, especially when only one in four deaths occurs in the attending physician's presence.**

Hospices' prohibition on assistance regarding medications says more about legal compliance than about moral reservations. Hospices are legally required to maintain some distance from physician-assisted death. Thus, there is a rather remarkable incongruity between the public rhetoric about hospice and the realities of hospice care. We began this essay with the observation—touted by both proponents and opponents of physician-assisted death—that over 88 percent of the persons who have died as a result of physician-assisted death in Oregon have been enrolled in hospice care. Proponents cite this figure to indicate that patients who choose physician-assisted death are receiving skilled quality care at the end of life and are not turning to it in desperation. Opponents cite this figure to argue that hospice is fully capable of attending to the holistic

needs of all patients as they near the end of life and that physician-assisted death is unnecessary. These competing lines of argument converge in a public narrative that hospice programs extensively participate in the implementation of the Death with Dignity Act.

Yet while most patients who choose physician-assisted death are enrolled in hospice care, they are not assisted by hospice programs when deciding, when contacting providers, or when procuring or administering medications. Furthermore, hospice staff members are unlikely to be present when patients ingest life-ending

medication. Hospice is distanced from physician-assisted death in a pronounced way. It is in the best interests of patients to be enrolled in a hospice program rather than to seek out physician-assisted death on their own, but one cannot infer from their extensive enrollment in hospice programs that hospice participation in physician-assisted death is extensive or substantively meaningful.

### **Models of Hospice Participation**

Comparing the views of hospice programs on the practical caregiving considerations discussed above and identifying the boundaries to participation that various hospices impose suggests four general models of hospice participation, ranging from full participation to no participation. The positions of four actual

(but unidentified) hospice programs illustrate these models.

*Full participation within the parameters of the law.* Our first example, hospice A, conceptualizes the professional and patient actions permitted by the Oregon Death with Dignity Act as a form of “physician-assisted death.” Upon patient inquiry, this hospice provides information about physician-assisted death, including the law and the process required of patients, and permits its staff to engage in conversation to explore a patient's interest in physician-assisted death. This hospice also directs patients to contact their attending physician or provides information about a patient education organization to help them identify an attending physician for the purposes of physician-assisted death, in addition to providing other patient services such as counseling or witnessing documents. This hospice—for reasons of mission and legal compliance—prohibits aid in securing or administering medications. However, it allows staff to be present with the patient and family members at the time the medication is ingested as part of its philosophy of being a “companion” on the patient's “journey.” If complications arise, the staff member is to address the “human” needs of the patient, leaving the “medical” needs to the prescribing physician.

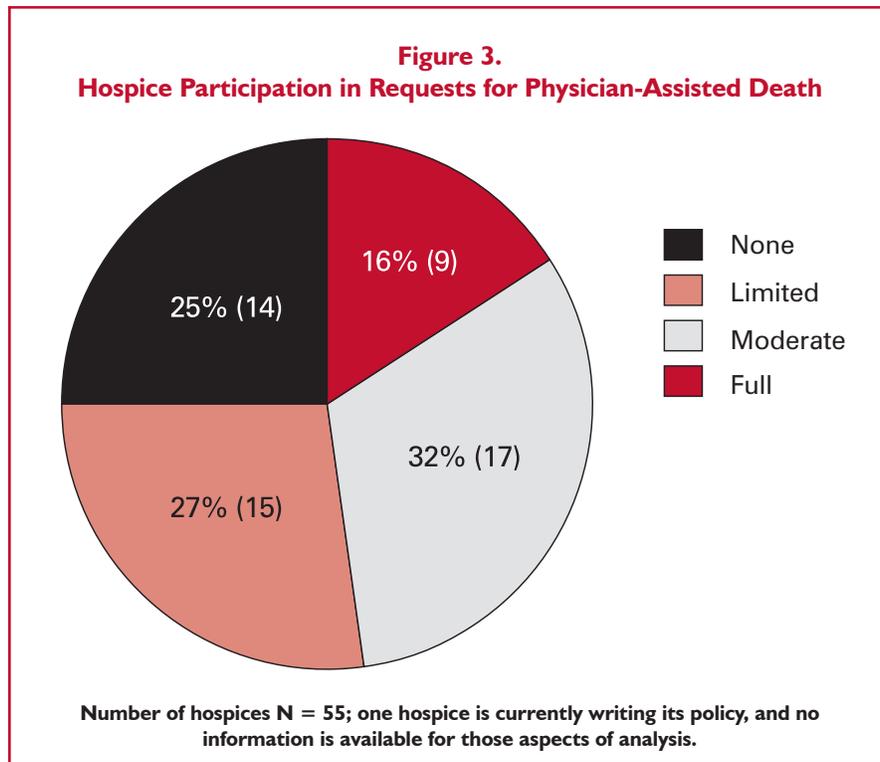
*Moderate participation.* Hospice B uses the language of “physician-assisted death” to refer to patient actions permitted by the law. It provides information about physician-assisted death if the patient requests it, while restricting which staff members can disclose the information. It also requires staff to engage in “neutral” disclosure. It directs the patient to seek out his or her attending physician but does not provide referral information to patient education organizations. As requested by patients or family, the hospice permits selected staff (excluding nurses) to be present during ingestion.

*Limited participation.* Hospice C uses the language of “physician-assisted

suicide” in its program materials. It refers inquiries from patients to attending physicians without conversation, assuming that the physician will explain the legal provisions and process guidelines. Thus, physician-assisted death does not become hospice-assisted death. This hospice does not assist with medications or the patient’s action and does not permit staff to be present when the medication is ingested. However, as governed by the values of providing customary hospice care and not abandoning the patient, the hospice continues to care for patients who seek physician-assisted death rather than arrange for a transfer of care, and it offers bereavement care to survivors.

*Nonparticipation or noncooperation permitted by the law.* Hospice D also promises quality hospice care to all its patients. However, hospice D frames the actions allowed by law as constituting “physician-assisted suicide,” thereby drawing a moral line against physician-assisted death. It refuses to participate or cooperate with patient requests regarding physician-assisted death and instead asks patients to respect its values and its position of nonparticipation. This hospice does not provide information regarding physician-assisted death to patients who inquire; it does not refer patients to physicians or patient education organizations, and it will not allow staff to be present when the patient takes life-ending medication. The hospice contends that quality hospice care renders physician-assisted death unnecessary as an end-of-life option, so its prohibition of assistance, while affirmed, has no practical import. Given this prohibitive stance, the hospice probably cares for relatively few patients interested in physician-assisted death.

These descriptions reflect the policy positions of four of the hospices we heard from in our study. The policies of the fifty-two other hospices represented in this study are more closely aligned to one kind of policy than another, even if complete conformity to all features of the model



hospice program is not always present. We conclude that most hospices in Oregon participate in the state’s Death with Dignity Act to some extent, but not to the fullest extent permitted by the law (see Figure 3).

### Toward Studied Neutrality

**W**e recognize certain limitations in our analysis. First, although we received responses from a geographically diverse group of hospice programs—including hospices in metropolitan areas, where the frequency of physician-assisted death is significantly higher than in rural areas—we did not receive requested materials from all Oregon hospices. Despite several contact efforts, we do not know whether the eight hospice programs that did not respond to our requests lack policies on physician-assisted death, disagree with the practice, or did not respond for some other reason. For those hospice programs that did respond, we do not understand in every case the background process by which the documents were developed—that is, whether the policies originated from

a common template, from a single-authored document, or from the deliberations of a committee process. Moreover, as some policies do not address a feature of the five caregiving considerations we examined, we do not know whether this policy silence reflects a failure to reach consensus among staff (as explained by one program with a comprehensive policy) or simply a lack of experience in addressing the issues (one hospice with a very thorough policy informed us that none of their patients had ever inquired about physician-assisted death).

We also acknowledge that what is stated in policy and what happens in practice can be two quite different things, as Carol Mason Spicer notes can be the case with ethical codes in general.<sup>11</sup> Practice can differ from policy because the documents are not used extensively in staff training, or because no policy can sufficiently address all of the questions staff might face in handling patient requests for physician-assisted death. While we tested our analysis through site visits and structured conversation with staff at two hospice programs, philosophy,

policy, and practice may diverge. Each of these limitations suggests a direction for further research and study.

Nonetheless, we can draw a number of important conclusions from the information we have collected. First, despite public and organizational discourse that portrays hospice care as monolithic, our study reveals a wide variety of both perspectives and practices in Oregon hospices regarding physician-assisted death. A patient who is admitted to a hospice program will receive standard hospice care but may receive different responses to inquiries about physician-assisted death, depending on the hospice.

As the Oregon law is primarily an exercise in patient self-determination and hospices emphasize neutrality in information disclosure, our evidence does not suggest that any hospice would directly intervene or interfere with a patient's inquiry about physician-assisted death. Still, in almost all instances, patients are informed about hospice's stance on physician-assisted death only after enrolling in the program and making a specific inquiry. Given this sequence of information disclosure, it is important to ask to what extent choosing a hospice means choosing a stance on physician-assisted death. Because of the different levels of hospice involvement with physician-assisted death, patients' choices regarding their treatment may be more or less facilitated by the specific hospice within which they enroll.

We find significant the fact that the positions and practices of hospice programs do not necessarily follow from their philosophy of care. While the values important to hospice care are named in the hospice documents, the correlation between these values and the policies and procedures the organizations follow is seldom direct. Core values (such as commitments not to abandon patients and to neither hasten nor postpone death) are necessarily in tension and do not lend themselves to a clear

consensual conclusion for hospice providers. Hospices' conclusions on policies regarding physician-assisted death generally lack a strong philosophical basis. The explanation may be that hospices' policies on physician-assisted death reflect concerns about legal compliance more than hospice philosophy. We are nonetheless led to question the substantive value of hospice philosophy for the specific policy conclusions and care practices regarding physician-assisted death.

The fact that no hospice is willing to assist in all phases of the physician-assisted death process points to two potentially troubling conclusions. First, the 88 percent hospice enrollment rate for patients who exercise their right to physician-assisted death does not reflect the extent of hospice participation and does not mean that patient care issues are resolved. If hospice staff generally do not disclose more than contact information, do not facilitate collaboration with prescribing physicians, and are not present at ingestion or death, then enrollment status cannot mean all patient care issues in the context of physician-assisted death are resolved. Patient care issues may just be emerging, especially when only one in four deaths occurs in the attending physician's presence.

Second, in the absence of data to the contrary, we must assume that the majority of physician-assisted deaths occur with neither a hospice staff member nor the prescribing physician present, which reveals a potential problem with patient care when complications arise. In practice, many deaths are attended by people affiliated with Compassion and Choices of Oregon. But if neither the physician nor a hospice caregiver is present when the patient takes the life-ending medication and dies, then the patients may feel abandoned by the very people who have assumed a fiduciary commitment to them in their terminal phase of life.

We find wisdom in Timothy Quill and Christine Cassel's

recommendation that organizations with position statements on physician-assisted death consider adopting a position of "studied neutrality."<sup>12</sup> The goal is to recognize the diversity of views among providers and patients and encourage open discussion of the issue. At the same time, organizations should both promote greater implementation of palliative care measures and present opportunities for providers to work with patients who make requests for physician-assisted death. We believe that—with the exception of Oregon hospices that have opted for a position of nonparticipation that is consistent with their values and the law—a policy of "studied neutrality" is compatible with the practices of most Oregon hospices respecting physician-assisted death. A position of "studied neutrality" also avoids the moral obfuscations that occur when hospice programs assert that they are not "directly" or "actively" participating in the law, and it can be a remedy for the many times in hospice care when issues of moral complicity surface. This approach can bring much-needed dialogue and transparency to a process that is unnecessarily opaque, permit hospice programs to acknowledge tensions in their core values, and promote efforts to assure congruence among values, policies, and procedures. Ultimately, serious engagement with the caregiving issues of physician-assisted death will enable critical reflection on the historical philosophy of care that constitutes hospice integrity.

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