OREGON HOSPICE NURSES' AND SOCIAL WORKERS' VIEWS AND EXPERIENCES WITH PATIENTS WHO REQUEST ASSISTED SUICIDE

by

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A THESIS

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Abstract

Background: In 1997, Oregon's Death with Dignity Act (ODDA) legalized physician-assisted suicide. The law allows a physician to prescribe a lethal dosage of medication for the purposes of self-administration to a competent, terminally-ill patient. Oregon is the only US state to allow this practice. To date, information about patients who have requested this option has come from surveys of physicians. Although 84% of the 129 Oregonians who have died by assisted suicide were enrolled in a hospice program, there is little information about hospice professionals' experiences with these patients. Hospice professionals may be able to provide information about these patients and their caregivers because they visit the patients frequently at the end of life, and are able to compare them to other dying patients.

Methods: In 2001 we mailed a questionnaire to all Oregon hospice nurses and social workers asking them their views on the ODDA and whether they would be willing to care for a patient who requested assisted suicide. Each respondent provided information on the most recent patient who had made an explicit request for assisted suicide and their understanding of why the patient made this request. Because hospice nurses and social workers may have given information on the same patients, hospice nurses were the primary informants for this study.

Results: Of 545 eligible hospice practitioners, 397 (73%) returned the survey including 71% of nurses and 78% of social workers. Forty-eighty percent of nurses and 71% of social workers support the ODDA. Only 3% (N = 10) of respondents, all nurses, would actively oppose a patient's choice on this matter and 10% would transfer the patient to another provider.

Since 1997, 179 (45%) respondents had cared for a patient who requested assisted suicide. Hospice nurses reported on 122 patient requests, including 82 who received a lethal prescription. Ninety-eight percent of hospice nurses discussed the patient's request with a coworker and 77% of patients were presented at a hospice interdisciplinary care conference. Respondents reported that the most important reasons patients who received a lethal prescription made the request was to control the circumstances of death, readiness to die, desire to die at home, seeing continued existence as pointless and fear of loss of independence. The least important reasons included depression, lack of social support, and fear of financially burdening others. Although these patients were concerned about burdening others, hospice nurses rated only 11% of their caregivers as more burdened by caregiving compared to other hospice family caregivers and only 3% as more financially burdened compared to other hospice family caregivers.

Conclusions: Although hospice professionals are divided in their views on legalized assisted suicide, they are overwhelmingly willing to care for these patients. Since legalization of assisted suicide in Oregon, many hospice staff have cared for a patient who requested assisted suicide. They rate desire for control as the most important reason patients make these requests. Enrollment in hospice may add to already existing safeguards in the Act.

Introduction

With enactment of the Oregon Death with Dignity Act (ODDA), Oregon became the first jurisdiction in the United States to legalize physician-assisted suicide. This law allows a treating physician to prescribe a lethal dosage of medication for the purposes of self-administration to a competent, terminally ill patient who is: (1) over 18 years of age, (2) an Oregon resident, (3) capable (i.e., having decision-making capacity), and (4) diagnosed with a terminal illness (i.e., an expected life of less than 6 months). In order to be eligible, the following steps must be completed: (1) the patient must make two oral and one written request over a 15 day period; (2) both the prescribing physician and a consulting physician must confirm the diagnosis, prognosis and whether the patient is capable; and (3) the physician must inform the patient of all feasible alternatives, including comfort care, hospice care and pain control. (4) If the primary or consultant physician believes that the patient's judgment is impaired by a psychiatric disorder such as depression, the patient must be referred for a mental health evaluation (www.ohd.hr.state.or/chs). Although the law was originally passed by ballot measure in 1994, a series of legal challenges delayed implementation. The law was upheld by the U.S. 9th Circuit Court, and 60% of Oregonians reaffirmed support in a second statewide vote. The ODDA was enacted in October 1997.

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1. "Physician-assisted suicide" is the generally accepted term describing a death that a competent person deliberately chooses and causes by self-administration of a substance (usually an oral agent), which a physician prescribes but does not administer.

2. "Euthanasia" is the generally accepted term describing administration by a physician (or another person) of a lethal medication, usually as an injection. Euthanasia is described as "voluntary" (competent patient makes the request); "nonvoluntary" (patient lacks decision-making capacity and makes no request); and "involuntary" (competent patient is killed against their wishes). The ODDA expressly forbids lethal injection and, therefore, all euthanasia.

Only two other jurisdictions in the world have legalized physician-assisted suicide. The Netherlands recently legalized physician-assisted suicide[1] as well as euthanasia,[2] but tolerated these practices for almost two decades. Studies of Dutch physicians who have participated in hastened death have been completed and published (van der Maas et al., 1991; van der Maas et al., 1995). The Northern Territories of Australia briefly legalized physician-assisted suicide in the mid 1990s, but only 7 patients availed themselves of the law before the Australian Parliament reversed the decision (Kissane et al., 1998).

One series of arguments against physician-assisted suicide are in the realm of ethics and morality and cannot be subject to scientific verification. Moral arguments for physician-assisted suicide include that autonomous individuals have moral authority over their lives, that both out of compassion and respect for autonomy, we should not coerce them into bearing suffering. Moral arguments against physician-assisted suicide include that Judeo-Christian tradition prohibits the direct taking of a human life except in the case of self defense, and that the ethics of medicine have emphasized preservation of life (Jonsen, Seigler and Winslade).

The political debate about these practices highlighted a series of speculations about why patients might choose physician-assisted suicide, and assumptions about attitudes of health care providers around this practice. Most objections to legalized physician-assisted suicide are a series of hypotheses about the clinical and social consequences. Furthermore, examination of the little available data underscored that most of what was asserted about the scope and risks of legalizing physician-assisted suicide was conjecture. Experts hypothesized that patients who pursue physician-assisted death are depressed, have pain, lack social support and are motivated by financial concerns or a desire not to burden their families (Chochinov et al., 1995; Emanuel and Daniels, 1996;

Faber-Langendoen, 1998; Foley, 1997; Hendin and Klerman, 1993; Koenig, 1993; Muskin, 1998; Singer and Siegler, 1990; Teno and Lynn, 1991; Truog and Berde, 1993). Commentators have suggested that requests for physician-assisted suicide would be rare if patients received adequate palliative care. Many have claimed that women, minorities and the poor, all of whom may have less access to health care, including palliative care options, would disproportionately choose legalized physician-assisted suicide (Alpers and Lo, 1995; Pellegrino, 1995). Others have suggested that physicians who agree to participate in physician-assisted suicide would be less likely to do so if they had greater knowledge, skills and comfort in caring for dying patients (Alpers and Lo, 1995; Foley, 1997). Finally, it has been proposed that legalized assisted suicide would undermine attempts to improve end-of-life care.

Studies of attitudes toward and experiences with physician-assisted suicide outside of Oregon: To date, studies from outside of Oregon only variably substantiate these speculations. There are no published studies of interviews with patients who later chose physician-assisted suicide or euthanasia either from the Netherlands, the United States or Australia that might help understand their reasoning. Studies from the Netherlands are based on surveys and interviews with participating physicians. Physicians from the Netherlands reported that patients chose physician-assisted suicide or euthanasia because of loss of dignity (57%), pain (46%), distressing mode of dying (46%), being dependent on others (33%) and tiredness of life (23%) (van der Maas et al., 1991; van der Maas et al., 1995). During the brief period in which the Northern Territories of Australia legalized physician-assisted suicide, there were seven deaths reported as case reports. Most patients were reported by physicians to have advanced cancer, be socially isolated and have some symptoms of depression (Kissane et al., 1998).

Meier et al. (1998), in a mailed survey of 1900 United States physicians, reported that 3.2% had written a lethal prescription, despite its illegality. Perceived reasons for the requests for physician-assisted suicide or euthanasia included: discomfort other than pain (79%), loss of dignity (53%), fear of uncontrollable symptoms (52%), actual pain (50%), loss of meaning in their lives (47%), being a burden (34%), and dependency (30%). Surveys of American and Canadian patients with cancer and acquired immunodeficiency syndrome variably demonstrate that higher education, depression, poor social support, pain, low religiousness, psychological distress, feeling unappreciated, and hopelessness characterize patients who endorse on surveys potential interest in hastened death, physician-assisted suicide or euthanasia (Emanuel et al., 1996; Breitbart et al., 1996; Chochinov et al., 1995; Wilson et al., 2000; Breitbart et al., 2000; Emanuel et al., 2000). None of the studies include information on whether any patients actually requested physician-assisted suicide. Importantly, these studies demonstrate that over 10% of these populations endorse a strong interest in physician-assisted suicide. In comparison, 1 in 1000 deaths in Oregon result from physician-assisted suicide. As such, risk factors associated with endorsing interest in physician-assisted suicide on a survey may be very different from risk factors for actually choosing physician-assisted suicide under legalized conditions.

Study of the Oregon Death with Dignity Act

Studies of health care providers in Oregon demonstrate differing levels of support for the ODDA. Surveys demonstrate that the law is supported by 51% of Oregon physicians eligible to prescribe, 54% of psychiatrists, 69% of emergency medical department physicians, and 78% of psychologists (Ganzini et al., 1996; Ganzini et al., 2000; Fenn and Ganzini, 1999; Schmidt et al., 1996).

The ODDA requires that all lethal prescriptions are reported to the Oregon Health Service (OHD), which publishes yearly statistics (www.ohd.hr.state.or/chs). The first five years of data included information on 129 deaths by physician-assisted suicide. The information is based on required reports submitted by prescribing physicians and subsequent interviews of all physicians by OHD staff. Physician-assisted suicide has accounted for between 6/10,000 and 13/10,000 deaths in Oregon since enactment. Compared to all Oregon residents who died, those who died by physician-assisted suicide were more likely to be college graduates, more likely to be Asian, are younger, more likely to die of cancer or amyotrophic lateral sclerosis, and more likely to be divorced. There was no increased risk of receiving a lethal prescription among African American, Hispanic or female Oregon decedents. Only two patients were uninsured. Ninety-four percent died at home and 23% were evaluated by a psychiatrist or psychologist. The most common reasons for requesting assistance with suicide were loss of autonomy (85%), inability to participate in activities that made life enjoyable (77%), loss of bodily functions (63%), worry about burdening others (34%), inadequate pain control (20%) and financial concerns (2%) (Sullivan et al., 2000; www.ohd.hr.state.or/chs). Physicians reported that many patients had more than one reason.

In 1999, we mailed surveys to all Oregon physicians who would potentially receive requests under the law in order to obtain information on all patients who had made explicit requests, not just those who had died by physician-assisted suicide. Of 4053 Oregon physicians eligible to prescribe under the ODDA, 2641responded (66% response rate), revealing that 144 (5%) had received a request for physician-assisted suicide since legalization in 1997 (Ganzini et al., 2000). These physicians reported on the outcome of 165 patients and gave complete information on 143 patients. Physicians who received requests for physician-assisted suicide rated loss of independence, poor quality of life, readiness to die, and wanting to control the circumstances of death as the most important reasons patients requested physician-assisted suicide (more than 50% for each reason). These physicians rated lack of social support as important in only 6% of requesting patients and concerns of being a financial burden as important in 11%. Thirty eight percent of requesting patients viewed themselves as a burden to others. Somewhat unexpectedly, only 20% of patients who requested physician-assisted suicide were rated by the physician as depressed. In most cases the physician instituted palliative care measures in an attempt to find an alternative to physician-assisted suicide. Referral to hospice was one of the most effective means of addressing the request, resulting in its retraction. Forty-six percent of patients on whom a substantive intervention such as hospice referral was made changed their mind compared to 15% who did not receive a substantive intervention. Yet patients who made the request while enrolled in hospice were more likely to obtain a lethal prescription than those who were not enrolled in hospice at the time of the request (Ganzini et al., 2000).

The only patient-based study of interest in physician-assisted suicide among Oregon patients focused on those with amyotrophic lateral sclerosis (ALS). ALS, also called Lou Gehrig's disease, is a disorder of progressive paralysis that results in death within 3-5 years. As per OHD, 10 patients with ALS have used the ODDA and ALS patients are 73 times more likely to die of physician-assisted suicide than all other Oregonians (www.ohd.hr.state.or/chs). A survey of 100 patients with ALS in 1995-1997 revealed that 44% intended to request a lethal prescription if legalized. Those who wanted a lethal prescription were more likely to be male, more hopeless (as measured on the Beck Hopelessness Scale), more educated, less religious, and rated their quality of life as poorer than those that did not, but did not differ in social support, depression, level of pain, suffering and severity of illness. Most family caregivers supported the patients' preferences (Ganzini et al., 1998; Ganzini et al., 1999). A recently completed study of 38 caregivers of ALS decedents, who participated in the first study, revealed that 12 (32%) patients explicitly discussed with a family member wanting physician-assisted suicide in the last month of life, but only 1 died by lethal prescription. The factors rated by patients in 1995-1997 that predicted desire for physician-assisted suicide in the last month of life were interest in physician-assisted suicide at the first interview (odds ratio [OR] = 11.9, 95% confidence interval [CI] =1.1-130.7) and hopelessness (OR = 12.5, 95% CI = 1.9-83.2). Of interest, neither study supported concerns that ALS patients who explicitly discussed wanting physician-assisted suicide were disproportionately worried about being a burden, depressed, suffering (as rated by the patients in 1995-1997), or dissatisfied with medical care as rated by their caregivers in 1999 (Ganzini et al., 2002).

A longitudinal prospective study of 162 cancer patients' attitudes toward physician-assisted suicide is close to completion. However, only two patients requested a lethal prescription, demonstrating that because the outcome is so rare, longitudinal studies of terminally ill, potentially eligible patients are unlikely to improve understanding the factors that predispose patients to physician-assisted suicide.

There are significant limitations of these data from Oregon. Both the survey and OHD data represent physicians' views of the patients, not patient interviews. These data have been criticized for the following reasons: (1) not all physicians had good knowledge of end-of-life care and may not have been skilled enough to successfully treat conditions which would have resulted in the requesting patient changing their mind, (2) the physicians may have been subjected to an inherent conflict of interest and may have overlooked reversible or treatable conditions related to the requests in order to justify giving a lethal prescription, and (3) the physicians may not have recognized depression or failed to explore existential and social issues (Rosenfeld and Breitbart, 2000; Hendin et al., 1998; Foley and Hendin, 1999; Hamilton, 2000). These criticisms are made by physicians who are certain that most requests for physician-assisted suicide would be rescinded if palliative care efforts were sufficient.

Physician-assisted suicide and hospice: Hospices deliver care in patients' homes including a full panoply of medical and psychosocial interventions focused on increasing comfort and helping patients prepare for death. Patients become eligible for hospice at the point they have less than six months to live and they are willing to forgo life-sustaining treatment.

Hospice in Oregon geographically serves every Oregon county. There are 50 Oregon hospices, all focused on care in homes, assisted living, and nursing homes. Only one small 20 bed inpatient hospice exists. Almost all Oregonians are financially eligible for hospice, either through Medicare, Medicaid, private insurance, or Veterans benefits. About 2% of nonpaying patients are accepted as charity cases. Currently about 37% of all deaths in Oregon occur in hospice, one of the highest proportions in the U.S. (Ganzini et al., 2002; Oregon Hospice Association, Ann Jackson, personal correspondence, 2003). The OHD data revealed that 84% of persons who chose physician-assisted suicide were enrolled in hospice (Sullivan et al., 2000; Ganzini et al., 2000). In OHD interviews of families of 19 patients who died by physician-assisted suicide in 1999, they reported that the median length of stay in hospice for their loved ones was seven weeks (Sullivan et al., 2001).

In hospice, nurses and social workers visit frequently, often daily as needed. We proposed that hospice nurses and social workers may be knowledgeable informants about these patients. Hospice nurses may, in fact, know the patients better than the physicians, because they see the patient often (sometimes daily). In addition, all patients are seen by clinical social workers who have expertise in psychosocial evaluations and often spend a great deal of time with patients requesting physician-assisted suicide. With their significant expertise in normative experiences among the dying, hospice nurses and social workers may be more likely to understand how these patients differ from those in hospice who do not request a hastened death. In addition, because they are not the prescribers and they do not need to justify the patient's receipt of a lethal prescription, they may be less biased in their reporting (or at least have a different set of biases).

The National Hospice and Palliative Care Organization opposes physician-assisted suicide and has a philosophy that specifically excludes this option (Beresford and Connor, 1999). The views of hospice nurses and social workers on physician-assisted suicide and the associated ethical conflicts have not been well investigated. One study of hospice *volunteers* (not in Oregon), found that 37% endorsed that physician-assisted suicide may be morally acceptable, and 4% had been asked to provide assistance to help a patient end his or her life (Zehnder and Royse, 1999). However, a report from the Oregon Hospice Association (OHA) ethics committee, and a small qualitative study suggested that hospice workers vary widely in their attitudes toward physician-assisted suicide (Campbell et al., 1995; Meisler and Miller, 2000). A qualitative study of 43 Oregon hospice workers conducted before enactment of the ODDA in 1997 focused on two interconnecting themes in hospices' dialogues regarding physician-assisted suicide: (1) whether hospice can provide sufficient comfort to eliminate requests for physician-assisted suicide and (2) whether an inherent value of life should preclude an individual's freedom of choice (Meisler and Miller, 2000).

Among the 50 Medicare certified hospices in Oregon, policies regarding how "involved" a hospice care provider can be in physician-assisted suicide also vary (Ann Jackson, Oregon Hospice Association, personal communication). In discussions among hospice providers, they share the perception that there is a difference between written policies in hospice which are quite liberal and allow substantial involvement by hospice professionals around the request, and "cultural policies" which discourage discussion of physician-assisted suicide with patients. There are no systematic studies of hospice care providers' views about physician-assisted suicide or their experiences with it. We hypothesized that hospice workers are not monolithic in their views, and that like physicians, personal religiousness influences their attitudes and willingness to participate in physician-assisted suicide.

Furthermore, we hypothesized that social workers, whose professional training is strongly focused on respect for autonomy would be more supportive of physician-assisted suicide than nurses in whom a strong basis of care and safety in practice may lead to more paternalistic attitudes. In addition, the professional societies that represent these groups differ around their codes of ethics specific to this issue. The American Nurses Association clearly states that "participation in physician assisted suicide is a violation of the code for nurses." (American Nurses Association, 1994) In contrast, the National Association of Social Workers (NASW) views client self determination as the primary guiding principle in social work practice. The code supports that physician-assisted suicide is "one of many options for persons with a terminal condition" and that the NASW "does not take a position concerning the morality of this decision." (National Association of Social Workers, 1999)

Summary: Oregon is the first and only state in the United States to legalize physician-assisted suicide. This situation represents an unparalleled social experiment. To date, much that has been written in the lay and medical literature has been speculative and rarely based on empirically-derived data. Information about patients' reasons for making these requests can be derived from physicians, hospice nurses, family and friends or the patients themselves. Currently there are substantial and potentially insuperable barriers to any studies that examine patients in the process of choosing physician-assisted suicide, or their families. A prospective cohort study of ill patients is an insufficient method of determining risk factors for physician-assisted suicide as requests are rare. Physician studies from Oregon have been informative regarding the scope and flaws of this practice, but have been challenged as inaccurate, self-serving, or so counterintuitive, that they must be mistaken (Hendin, 2000; Foley and Hendin, 1999; Rosenfeld and Breitbart, 2000). Data from a study of hospice professionals in Oregon may fill gaps in this knowledge.

Physician-assisted suicide has been conceptualized as an issue between patients and physicians and as an alternative to hospice. In Oregon, however, most physician-assisted suicides occur within hospice and anecdotal information suggests that those nurses and social workers experience many ethical dilemmas. In the face of their unprecedented involvement in physician-assisted suicide, we proposed this study to address gaps in knowledge.

Objectives and Hypotheses of Study

Objective 1. Document the views of Oregon hospice nurses and social workers on physician-assisted suicide and the ODDA, their willingness to care for these patients, and how they would respond to a patient who requested physician-assisted suicide.

Hypothesis 1A. Social workers will be significantly more supportive of the ODDA than nurses.

Hypothesis 1B. Professionals who rate religion as "important" in their lives will be significantly more likely to oppose physician-assisted suicide.

Objective 2. To determine hospice nurses' and social workers' views on why patients chose to hasten death through physician-assisted suicide.

Hypothesis 2A. Hospice professionals will report that the most important reasons patients will choose physician-assisted suicide will include enhanced sense of control and independence at the end of life, existential concerns, concerns about burdening family, and perceptions of poor quality of life.

Hypothesis 2B. Depression, poor social support, and financial concerns will be relatively uncommon reasons for choosing physician-assisted suicide.

Objective 3. To determine how hospice nurses and social workers rate the quality of life in final weeks of life in patients who hasten death by physician-assisted suicide.

Objective 4. To compare hospice nurses' perceptions of the reasons for the request and the outcomes (quality of dying) among patients who received lethal prescriptions compared to those who requested but did not receive lethal prescriptions.

Objective 5. To document hospice care providers' perceptions of barriers to these death-hastening acts, perceptions of impact of death-hastening acts on the family, and resources/consultation used by hospice nurses to evaluate patients making requests for physician-assisted suicide.

Methods: This project is a descriptive, cross-sectional study of Oregon hospice nurses' and social workers' views on and experiences with hastened death by physician-assisted suicide since enactment of the ODDA in 1997. Study co-investigators were Elizabeth R. Goy, Ph.D.; Theresa A. Harvath, R.N., Ph.D.; Lois L. Miller, Ph.D., R.N.; Ann Jackson, M.B.A.; and Molly A. Delorit, B.A.. Funding for the study was received from the Greenwall Foundation. These results are based on a mailed, self-administered survey sent to hospice nurses and social workers who care for Oregon patients. All 50 Medicare-certified hospices in Oregon, as well as two hospices in Washington and Idaho who cared for Oregon patients, were identified. Oregon's one inpatient hospice and prison hospice were excluded. Hospice directors were asked through the Oregon Hospice Association to share the names of nurses and social workers whom they employed. The inpatient hospice was excluded because it admitted patients from a variety of in-home hospices, leading to potential duplication of reports about patients. The prison hospice is also very small, the population seems distinctly different from other hospices, and there remains the question of whether or not prisoners have sufficient autonomy to receive lethal prescriptions under the ODDA. Fifty hospices submitted the names of all eligible employees (N = 533). Two hospices submitted 21 names and informed us that they would deliver surveys to the other 19 eligible employees who did not wish to release their names.

The questionnaire was based on a previous survey sent to Oregon physicians, as well as a review of literature regarding expert predictions of requests for physician-assisted suicide; review of qualitative interviews with Oregon physicians who had received requests for physician-assisted suicide and commented on the reasons patients requested; discussions with hospice nurses about their experiences; and clinical psychiatric interviews performed by Dr. Ganzini of 15 patients who had made explicit requests for physician-assisted suicide under the ODDA. The content was reviewed by Dr. Tim Quill, a nationally renowned expert in this area, as well as members of the Research Design Course offered by the Masters of Public Health program at the Oregon Health & Science University. After pretesting this instrument with six hospice nurses and social workers, some questions were clarified, others deleted, and patient demographic information was minimized because hospice employees were uncomfortable revealing potentially identifying information. Questions on the survey included (survey appended)

***Demographic information on survey respondents*:**

1. Profession, age, gender, length of time in hospice nursing or social work, population of practice, religiousness, and spirituality. Religiousness and spirituality were measured by a Likert-type scale, with end-points labeled "religion (spirituality) is very important to me" (10) and "religion (spirituality) is not important to me" (0). These measures of religiosity were used in the survey of physicians' experiences with the ODDA.
2. Attitudes toward the ODDA, changes in support or opposition since the Law passed in 1994, whether the nurse or social worker would actively support or oppose a patient's choice for physician-assisted suicide, or would transfer or continue care for a requesting patient. Several of these questions were identical to those used in the physician ODDA survey.

Information on patients:

The hospice nurses and social workers provided information on the one most recent patient who made an explicit request for physician-assisted suicide since November 1997 (date of legalization) and had since died. Our experience with the physician survey showed that asking respondents to give extensive information about more than one patient resulted in decreased survey response. For each case, we asked the following information about the patients:

1. Demographic and disease characteristics of the patient including age, gender, marital status, size of community, terminal diagnosis.
2. Outcome of the patient (e.g., died of physician-assisted suicide, died from a terminal disease, uncertain).
3. Barriers to receiving physician-assisted suicide including the patient did not meet the criteria in the law, died before completing requirements of the law, no willing physician, changed mind, suicided by other means – these were adapted from the physician questionnaire.
4. The reasons the patient desired to hasten death by physician-assisted suicide, including physical symptoms (e.g., pain, confusion, depression, nausea, dyspnea, loss of bowel or bladder function, fatigue) or fear of these symptoms worsening; readiness to die; inability to care for self; inability to engage in pleasurable activities; witnessing bad deaths; perception of self as a burden or financial drain; concern about loss of dignity or independence; lack of social support; poor quality of life; inability to pursue previously pleasurable activities; desire to control circumstances of death; wishing death at home; seeing life tasks as complete or continued existence as pointless. These were measured via a 5-point Likert-type scale ranging from 1 =

"not at all important in decision to request a lethal prescription" to "5 = very important in decision to request a lethal prescription." Respondents marked a separate box if they did not know if the reason was important, or did not actually have a conversation with the patient or family about the reason. The hospice practitioners compared the physician-assisted suicide-requesting patients to other hospice patients on some characteristics using a 1-5 scale with 1 = "Much less compared to other hospice patients," 3 = "About the same as other hospice patients," and 5 = "Much more compared to other hospice patients. Characteristics measured included pain, dyspnea, depression, anxiety, fears of loss of independence, control of bladder or bowel function, mental ability, suffering, peacefulness and tiredness of life.

5. How the hospice nurse evaluated the patient including whether they obtained consultation from or discussed the case with the hospice social worker, discussed the issue with the primary care physician, reviewed the case in an interdisciplinary care conference, discussed the case with a supervisor, discussed it with another hospice provider or sought consultation from a mental health practitioner (psychiatrist, psychologist or mental health nurse practitioner).
6. Overall quality of dying; questions are from a previous physician study and our ALS caregiver study. Respondents rated on a 10-point scale, with endpoints labeled, the patient's overall peacefulness (0 = very much at peace, 9 = not at all at peace), suffering (0 = no suffering at all, 9 = severe, unremitting suffering), and pain (0 = no pain at all, 9 = severe, unremitting pain) in the two weeks before death, and the overall quality of dying (0 = very bad death, 9 = very good death), as well as their

confidence that they could facilitate a good death from the client's point of view (0 = not confident, 9 = very confident).

7. Attitudes of the family about the patient's preferences for physician-assisted suicide including whether significant others were aware of request, accepting of decision, or the decision was influenced by family. The hospice practitioners compared the family caregivers of physician-assisted suicide patients to other hospice family caregivers on some characteristics using a 1-5 scale with 1 = "Much less compared to other hospice families," 3 = "About the same as other hospice families," and 5 = "Much more compared to other hospice families. Measured characteristics included feeling burdened by caring for ill family member, feeling burdened by cost of care for ill family member, finding positive meaning in caring for family member, accepting ill family member's death, and feeling emotionally distressed.

The initial surveys were mailed between July and September 2001 after funding was obtained from the Greenwall Foundation. We followed up with a reminder postcard, a second copy of the survey and a personalized reminder letter. We sent 19 anonymous employees two sets of questionnaires via their hospice directors. Each questionnaire included a $10 check or, for employees whose full name was not supplied, an offer of $10. Surveys were accepted through January, 2002. To allow for tracking of the questionnaires, return envelopes were coded with an identifying number. The survey was separated from the envelope on receipt, and recoded with a new number, rendering it anonymous. As such, no survey can be tracked back to either the individual or the hospice. Because the survey was anonymous, it was exempted from the requirement for informed consent by the institutional review board at the Portland Veterans Affairs Medical Center.

Data analysis: In some cases a nurse and a social worker may have cared for the same patient; therefore, nurses' responses are reported separately from social workers' responses. In some cases two nurses may have reported on the same patient, although most hospices assign a primary nurse for each patient. However, based on demographics data, there were no duplicates among patients who received lethal prescriptions. In other words, each nurse reported an independent observation. Because nurses give continuous care and have more contact with patients and their families compared to social workers, they are the primary informants for the purpose of this study. Summary statistics are presented as frequencies and proportions for categorical variables. Respondents' ratings of the importance of the reasons were not normally distributed and are presented as medians with interquartile ranges. Social workers and nurses were compared on these measures by Mann-Whitney U statistic. Other continuous, normally distributed measures are presented as means with standard deviations and compared with Student's t-test, or one way analysis of variance (Daniel, 1999).

Logistic regression was used to understand, among requesting patients, determinants of who received a lethal prescription versus who did not, as viewed by nurses. Variables associated with this outcome were included in the regression if univariate P values were < 0.15. Variables considered for inclusion were nurses' attitudes regarding the ODDA, and whether they felt confident they could help the patients; patient characteristics including demographic and disease characteristics; reasons for the choice; suffering and pain in the two final weeks of life; and views of the family. Patient demographic variables were entered as a block first, followed by all other variables using the Forward Wald procedure (Hosmer and Lemeshow, 1989). Results are presented as odds ratios (OR) with 95% confidence intervals (CIs). All P values are two-sided. Statistical analyses were performed on SPSS.

Results

Twenty eight hospice employees on the original list of 573 staff were excluded because they no longer worked at the hospice or did not care for Oregon patients. Of 545 potential respondents, 397 (73%) returned the survey, including 307 of 429 nurses (71%) and 90 of 116 social workers (78%). (Six of the respondents who were identified by the hospice social worker group were self-identified as other types of counselors with nonsocial worker degrees, but were included in the social work group because the similarity of training and job functions.) One respondent failed to mark profession and is excluded from all analyses. Response rates per hospice varied from 25% to 100%. There was no other available demographic information on non-respondents (besides profession) that might allow comparison of those who complete the survey and those who did not.

Table 1 shows characteristics of 307 hospice nurses and 90 social workers. Overall, these professionals were predominantly women, with less than one quarter working in the Portland Metropolitan area. They had worked in hospice for, on average, seven years. They rated themselves as highly spiritual but moderately religious. Over two thirds had not changed their views on the ODDA since 1994, but those who had were twice as likely to be more supportive than more opposed. Most respondents would take a neutral position about a patient's decision for physician-assisted suicide; only 10 respondents, all nurses (3% of sample), would oppose a patient's choice. Twelve percent of nurses would transfer a patient who received a lethal prescription to another hospice provider, compared to 2% of social workers. However, 71% (78 of 110) nurses who opposed physician-assisted suicide would continue to care for a requesting patient.

Nurses and social workers were compared on demographic and attitude variables (Table 1). Nurses were more likely to be female and to rate religion as more important in their lives than did social workers. As predicted, nurses were significantly less supportive of ODDA; this, however, may be in part related to religiousness as opposed to our hypothesis that this was related to training. Consistent with their views on ODDA, nurses were more likely to transfer the patient than social workers, but with only a trend to respond to the request with opposition.

Table 2 examines characteristics associated with support or opposition to the ODDA compared to social workers; as previously noted, social workers were more supportive of the ODDA than nurses. Otherwise, consistent with our hypothesis, the only significant variable associated with this support/opposition to ODDA was religiousness.

Since November 1997, 179 respondents (45%) had cared for a patient who explicitly requested a lethal prescription from a physician under the ODDA; 172 hospice practitioners, including 122 nurses and 50 social workers, submitted information about the patient. Hospice professionals who supported the ODDA were more likely to have cared for a requesting patient. Social workers reported on 38 patients and nurses on 82 patients who actually received a lethal prescription. Among those who received a lethal prescription, nurses reported that 55 died by physician-assisted suicide, 17 died from other causes, and in 10 the cause of death was uncertain.

The hospice nurse discussed the patient who received a lethal prescription with at least one coworker in 80 cases (98%) including: hospice interdisciplinary care conference attendees in 63 cases (77%), the hospice social worker in 60 cases (73%), and the patient's physician in 45 cases (55%). Hospice nurses reported that 50 (61%)

patients were evaluated by a clinical social worker and 40 (49%) were evaluated by a psychologist, psychiatrist or mental health nurse practitioner.

Views of patients who received lethal prescriptions: Nurses reported on the 82 patients who received a lethal prescription (Table 3). Their mean age (+/- SD) was 63.6 +/- 11.5. There were 41 men and 41 women. Sixty eight (83%) had a malignancy as their terminal diagnosis, 10 (12%) had cardiopulmonary disease, and 7 (9%) had neurological disease. Forty three (52%) were married, 37 (45%) were not married. Thirty five (43%) resided in a rural area or town with a population of less than 25,000; 28 (34%) in a town with a population between 25,000 and 250,000; and 19 (23%) in a city with a population of more than 250,000.

Hospice nurses perceived the most important reasons that patients requested lethal prescriptions included wanting to control the circumstances of death, wanting to die at home, seeing continued existence as pointless, and being ready to die (Table 3). Hospice nurses reported that 77% of patients who received a lethal prescription were more fearful of loss of control of circumstances of death compared to other hospice patients, whereas 8% were less fearful than other hospice patients. Sixty two percent were more likely to be concerned about loss of independence compared to other hospice patients, whereas 9% were less concerned about loss of independence compared to other hospice patients (Figure 1). Depression and other psychiatric disorders, lack of social support, and concerns about being a financial drain were, according to nurses, relatively unimportant reasons patients made these requests.

Hospice social workers perceived desire to control the circumstances of death, wanting to die at home, loss or feared loss of independence, and loss or feared loss of dignity as the most important reasons patients requested prescriptions for lethal medications; all these reasons had median scores of 5. They ranked lack of social support and depression as the least important reasons, both with median scores of 1. Social workers rated fear of loss of dignity as more important (median = 5, interquartile range 2, 5, p = 0.05) and seeing existence as pointless as less important (median score = 4, interquartile range 3, 5, p = 0.05) than nurses.

Hospice nurses assessed the overall pain levels in the last two weeks of life of patients who received lethal prescriptions as 3.1 +/- 2.3 on a 0-9 scale. Pain or fear of pain was important in many requests. Only 15% of nurses, however, rated the patient as having more pain, on average, compared to other hospice patients, whereas 42% were rated as having less pain on average than other hospice patients (Figure 1). Other physical symptoms such as fatigue and dyspnea were only moderately important reasons for the request, and nurses reported that 58% of patients who received a lethal prescription had less dyspnea compared to other hospice patients.

Hospice nurses reported that 39 patients requested but did not receive a lethal prescription and in one case the nurse did not know if the patient received a prescription. Reasons for not receiving a prescription included that the patient could not find a physician willing to prescribe the medication (N = 13), did not meet the law's criteria (N = 4), changed his/her mind (N = 13), died before completing the law's requirements (N = 12), and/or chose to hasten death by voluntary discontinuation of food or fluids (N = 7). Some nurses noted more than one reason. Patients who requested but did not receive a lethal prescription were older (69y +/- 12y v 63y +/- 11y, *P* = 0.03); they were assessed as more depressed (N = 27, median = 2, interquartile range = 1, 4, p = 0.039), and as placing less value on dying at home (N = 29, median = 4, interquartile range = 2.5, 5, p = 0.007) compared to those who did receive a lethal prescription. Two thirds of patients whose family opposed physician-assisted suicide were unable to obtain a lethal prescription compared to 22% of those whose family supported the choice ($\chi2 = 10.7$, df = 1.0, $P = 0.001$). Nurses rated the quality of death as higher in those who received a lethal prescription (6.8 +/ -2.7), than those who requested but did not receive one (5.5 +/- 3.0, p = 0.021); however, there was no significant difference between these two groups in overall suffering, pain, and peacefulness in the two weeks before death.

Logistic regression was used to understand which variables predicted actually receiving a lethal prescription among requesting patients. Variables considered for regression analysis based on univariate P values included patient's gender ($P = 0.08$), nurses' attitudes about the ODDA ($P = 0.09$), family's attitude regarding choice of physician-assisted suicide ($P = 0.001$), patient's age ($P = 0.03$), reasons for choosing physician-assisted suicide including pain ($P = 0.13$), depression ($P = 0.04$), wanting to die at home ($P = 0.007$) and the nurse's confidence that she could facilitate a good death based on patient's point of view ($P = 0.06$). Patient's age and gender were entered into the equation first as a block, followed by all other variables in the second block. Because of the large number of missing variables under reasons for choice (nurses were asked to not complete this data if they had not discussed it), the equation was modeled both with and without these variables. P to enter was set at 0.15, P to remove at 0.02. In both models only family opposition predicted which patients among those who requested did not receive a lethal prescription (Wald = 8.24, df = 1, $P = 0.004$, OR = 0.15, 99% CI = 0.04-0.548).

Views of families: Over 85% of hospice nurses observed that all family members of patients who received a lethal prescription knew and were, in general, accepting of the patient's decision to pursue physician-assisted suicide (Table 4). Hospice staff personally spoke to a family member in three-quarters of the cases. Despite patients' concerns about burdening family members, only 11% of hospice nurses assessed the family as more burdened by caregiving and 3% assessed the family as more financially burdened, compared to family caregivers of other patients receiving hospice services (Figure 2). As noted above, family support or opposition to physician-assisted suicide for the patient was the most important predictor of whether or not the patient received a lethal prescription. Hospice nurses reported that in 55 cases (67%) the patient's decision was not influenced by the family, in 22 (27%) it was somewhat influenced, and in 3 (4%) it was influenced a great deal, (N = 2 missing). Eighty-four percent of nurses rated the caregivers as finding as much or more positive meaning in caring for the ill relative compared to families of other hospice patients. Families of patients who received a lethal prescription were overall more accepting of and prepared for the ill family members' death, though somewhat more likely to be emotionally distressed, compared to families of other hospice patients (Figure 2). As noted previously, family opposition to physician-assisted suicide was the most important factor in why patients did not receive prescriptions. Our qualitative study of physician experiences suggests that physicians are risk aversive and fear exposure if proceeding with physician-assisted suicide. Also, they are concerned about emotional damage to family members through physician-assisted suicide.

Discussion

Similar to other studies of Oregon health professionals about physician-assisted suicide, our study demonstrates heterogeneity among hospice professionals in their attitudes about the ODDA. Despite the ethos of hospice, which includes that death "shall not be hastened or postponed," and firm opposition to physician-assisted suicide by the National Hospice and Palliative Care Organization and their own professional organization, Oregon hospice nurses are divided on this issue with 48% supporting and 36% opposing legalized physician-assisted suicide. The views of hospice nurses are similar to Oregon physicians in whom 51% support the ODDA and 32% oppose it (Ganzini et al, 2000). On the other hand, social workers demonstrate substantially more support of the ODDA. The only factor associated with support or opposition to the ODDA besides profession was religiousness, which was strongly associated. Similar to other studies in Oregon, neither gender nor age was associated with views on the ODDA. We also found that location of practice had no influence on nurse and social workers' views. This result is in contrast to the physician survey which demonstrated that rural physicians were much less inclined to prescribe under the Act.

Since legalization in 1997, physician-assisted suicide in Oregon is rare, accounting for between 6/10,000 and 13/10,000 deaths per year (OHD, 2003). Despite its rarity, 45% of the Oregon hospice nurses and social workers who responded to our survey had cared for a patient who explicitly requested a lethal prescription from a physician under the law and 30% had cared for a patient who received one. According to hospice professionals, two domains appear important as reasons patients make the request. The first is related to autonomy: desire for control, desire to remain independent, worries about inability to perform personal care and wanting to die at home. The second domain is existential: feeling ready to die, seeing continued existence as pointless, life tasks completed, sense of dignity and poor quality of life. Physical suffering was only modestly important as a reason, with 42% of nurses reporting the patient had less pain than most other hospice patients and 58% reporting less dyspnea than other hospice patients. This is consistent with studies from the Netherlands in which physicians reported that pain was the sole reason for physician-assisted death in only 5% of cases.

Patients who received a lethal prescription were concerned about burdening their family. Their families, however, were assessed as less likely to be burdened by care, including cost of care, and more likely to find positive meaning in caregiving compared to other families of hospice patients. Among these patients, fears of being a burden may reflect their own distaste of dependence during the dying process, rather than communications from their families.

Outside of Oregon, one of the most consistent findings in studies of ill and dying patients is that depression elevates the risk of preference for hastened death (Emanuel et al., 2000; Brown et al., 1986; Breitbart et al., 2000; Breitbart et al., 1996; Wilson et al., 2000; ODDA, 1994). However, the 9% to 26% of cancer patients who indicate preference for hastened death in these surveys may differ substantially from the 0.4% of terminally-ill cancer patients who die by physician-assisted suicide in Oregon each year (OHD, 2003; Emanuel et al., 2000; Brown et al., 1986; Breitbart et al., 2000; Breitbart et al., 1996). Oregon patients who desire physician-assisted suicide place a high value on dying at home. Many studies demonstrating the relationship between depression and interest in physician-assisted suicide, however, are performed not at home but in inpatient palliative care units. As such, they may not be representative. In contrast to the high prevalence of depression (40-60%) in patients who express an interest in physician-assisted suicide outside of Oregon, Oregon physicians reported that 20% of requests for a lethal prescription were from depressed individuals, and no depressed individual received a lethal prescription (Ganzini et al., 2000). Hospice social workers, who have expertise in evaluating mood disorders in terminally-ill patients, rated depression as the least important of all 21 possible reasons for requesting physician-assisted suicide. A recently completed qualitative study of physicians who receive requests supports that these patients are determined, focused and energetic in their attempts to obtain these prescriptions and marshal these energies to pursue physician-assisted suicide even in the face of physician and family reluctance (Ganzini et al., in press). Depressed patients, although potentially preferring death, may be too apathetic, ambivalent and ineffective to obtain a lethal prescription. Thus, although depressive disorders may be a risk factor for wanting physician-assisted suicide, they may render patients ineffective in convincing others that they should receive a lethal prescription.

The ODDA has safeguards to ensure that patients who choose physician-assisted suicide are terminally ill, have adequate decision-making capacity, are not influenced by depression or acting impulsively, and have been offered alternatives (ODDA, 1994). Our results suggest that hospice enrollment may offer additional protections. Most patients are discussed with coworkers, often at interdisciplinary care conferences. Many are evaluated by clinical social workers with expertise in end-of-life care. In Oregon, hospice enrollment does not appear to be a barrier to receiving a lethal prescription, and even hospice professionals who oppose legalization of physician-assisted suicide rarely oppose a patient's choice on this issue.

There are some limitations to this study:

Limits in generalizability: We recruited all hospices. As such, there is no sampling bias at this level. As reported by OHD, 20-25% of patients who choose physician-assisted suicide are offered hospice but refuse it. The views of 27% of hospice practitioners who did not respond to the survey are not represented. The reasons patients choose physician-assisted suicide, the methods for evaluations and responses of families may differ markedly under legal versus illegal conditions. Even though Meier et al. (1998) reported that 3% of U.S. physicians have participated in physician-assisted suicide or euthanasia, our data may not be applicable outside of Oregon.

Validity: Although we asked respondents to base information about the patient's reasons for requesting physician-assisted suicide on actual conversations with the patient or family, the degree to which hospice professionals accurately represent their patients' views is unknown. These reports are based on nurses' perceptions and memories of deaths that may have occurred up to four years previously. Because this survey was not proceeded by qualitative interviews, we may not have asked some information important for understanding hospice professionals' views and experiences. Furthermore, there may be errors in question design. However, almost half of the questions were previously used and new questions received several levels of review and pretesting (Ganzini et al., 1996; Lee et al., 1996; Fenn and Ganzini, 1999; Schmidt et al., 1996). Criticisms of our previous study were not based on biased questions, but on biased respondents. Review of the survey responses did not indicate uncertainty of the meaning of the questions on the part of the respondent.

This study is not population-based. Between 1998 and 2001, the Oregon Health Division reported that 71 individuals in hospice died by lethal prescription. The hospice nurses we surveyed in our study provided information on 55 patients who died by physician-assisted suicide in the same time period (Oregon Human Services, 2002). Though in most hospices one nurse assumes the primary care taking role from enrollment until death, we cannot be certain that two nurses did not report on the same patient. In addition, each respondent was asked to provide information on only the most recent requesting patient. As such, some cases may have been missed.

Summary and Conclusion

Both opponents and supporters of physician-assisted suicide agree that this option should be utilized as a measure of last resort. Attempting to develop alternatives requires a good understanding of the reasons for these requests. Many who oppose physician-assisted suicide claim they have done so because they conceptualize these patients as needing better palliative care and depression treatment, not a lethal prescription. Our studies suggest that these approaches would be misguided as many patients who want physician-assisted suicide are receiving excellent palliative care in hospice and are not depressed. Oregon hospice nurses and social workers validate Oregon physicians' perceptions that patients request physician-assisted suicide in order to control circumstances of death, maintain independence, die at home, and because they assess their quality of life as poor and are ready to die. Effective interventions must be in the realm of the spiritual to assist patients in finding meaning. Hospice's focus on comfort may not meet these patients' extensive needs for control and alternatives should be developed.

The literature on this issue has reflected a presumption that hospice is a mutually exclusive alternative to assisted suicide. In fact, in Oregon they co-occur. Only a small number of professionals thought that patients who want assisted suicide should be discharged from hospice. Despite the lack of universal support for the ODDA among Oregon's hospice professionals, they are willing to care for patients who make this choice. The improved care for these individuals may partially explain the very low rate of physician-assisted suicide despite legalization.

Table 1. Characteristics of 397 hospice nurses and social workers

Characteristics	**Nurses** **N = 307**	**Social Workers** **N = 90**	**P Value**
	Mean (SD)	Mean (SD)	
Age, y	49.3 (9.4)	49.2 (8.6)	0.95
Length of hospice employment, y	7.0 (5.2)	6.4 (5.3)	0.37
Importance of religion	6.7 (3.6)	4.8 (3.7)	< 0.001
Importance of spirituality	9.3 (1.6)	9.1 (1.8)	0.51
	No. (%)	No. (%)	
Gender			< 0.001
Men	16 (5)	18 (21)	
Women	290 (95)	70 (80)	
Missing	1 (0)	2 (2)	
Size of population served by hospice			P = 0.66
Rural/small town (population < 25,000)	135 (44)	32 (38)	
Medium sized city (population 25,000 - 250,000)	104 (34)	32 (38)	
Large city (population > 250,000) or suburb	65 (21)	20 (24)	
Attitudes toward ODDA			P = 0.001
Strongly support	59 (19)	29 (33)	
Support	88 (29)	33 (38)	
Neither support nor oppose	50 (16)	14 (16)	
Oppose	45 (15)	6 (7)	
Strongly oppose	65 (21)	6 (7)	

Table 1. Characteristics of 397 hospice nurses and social workers (cont)

Characteristics	**Nurses** N = 307	**Social Workers** N = 90	**P Value**
	No. (%)	No. (%)	
Has support for or opposition to ODDA changed since 1994			P = 0.09
More supportive	50 (16)	22 (25)	
No change	230 (75)	61 (69)	
More opposed	29 (9)	5 (6)	
Response to a patient's request for physician-assisted suicide			P = 0.09
Actively support in some or all cases	103 (33)	38 (42)	
Neither support nor oppose	190 (63)	50 (58)	
Actively oppose in most or all cases	10 (3)	0	
Continue care or transfer patient requesting physician-assisted suicide			P = 0.03
Continue to follow	255 (84)	85 (98)	
Transfer to other provider	36 (12)	2 (2)	
Other	14 (5)	0 (0)	

Table 2. Factors associated with position on ODDA

Variable	Support (N = 209)	Neutral (N = 64)	Oppose (N = 122)	P Value
	No. (%)	No. (%)	No. (%)	
Gender*				P = 0.31
Male	22 (11)	5 (8)	7 (6)	
Female	186 (89)	58 (92)	115 (94)	
Location of practice†				P = 0.08
Rural/small town	83 (40)	25 (40)	59 (49)	
Medium city	68 (33)	27 (44)	41 (34)	
Large city	56 (27)	10 (16)	20 (17)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Age, y	48.9 (9.1)	51.1 (9.9)	50.0 (8.9)	P = 0.24
Years in hospice practice	6.7 (5.2)	6.7 (5.5)	7.2 (5.2)	P = 0.69
Importance of religion‡	4.8 (3.5)	6.3 (3.6)	8.8 (2.4)	P < 0.001
Importance of spirituality‡	8.9 (1.9)	9.3 (1.5)	9.7 (1.1)	P < NS

* Missing = 2.

† Missing = 8.

‡ Rated on a 0-9 scale, with 0 = not important and 9 = very important.

Table 3. Reasons for requesting a lethal prescription among hospice clients who received one*

Reason client wanted a lethal prescription	Hospice Nurses (N = 82)			Social Workers (N = 38)		
	No. of Responses†	Median Score‡	IQR§	No. of Responses†	Median Score‡	IQR§
To control circumstances of death	77	5.0	5.0, 5.0	34	5.0	4.0, 5.0
Ready to die	73	5.0	4.0, 5.0	30	4.0	3.0, 5.0
Wanted to die at home	69	5.0	3.0, 5.0	26	5.0	3.0, 5.0
Saw existence as pointless	66	5.0	3.0, 5.0	28	4.0	3.0, 5.0
Loss of or fear of losing independence	75	4.0	4.0, 5.0	32	5.0	4.0, 5.0
Poor quality of life or fear of poor quality of life	75	4.0	4.0, 5.0	32	4.5	4.0, 5.0
Loss of or fear of losing dignity	73	4.0	3.75, 5.0	31	5.0	4.0, 5.0
Pain or fear of worsening pain	75	4.0	3.0, 5.0	30	4.0	3.0, 5.0
Inability to perform personal care or fear of inability	70	4.0	3.0, 5.0	32	4.0	4.0, 5.0

Table 3. Reasons for requesting a lethal prescription among hospice clients who received one * (cont)

	Hospice Nurses (N = 82)			Social Workers (N = 38)		
Reason client wanted a lethal prescription	**No. of Responses†**	**Median Score‡**	**IQR§**	**No. of Responses†**	**Median Score‡**	**IQR§**
Perceived self as burden to others or fear of becoming a burden	71	4.0	3.0, 5.0	28	4.0	3.0, 5.0
Unable to pursue pleasurable activities	67	4.0	3.0, 5.0	25	4.0	3.0, 4.0
Life tasks complete	63	3.0	2.0, 5.0	24	3.0	2.0, 4.0
Fatigue or fear of worsening fatigue	67	3.0	2.0, 5.0	25	3.0	3.0, 4.0
Loss of or fear of losing bowel/bladder function	65	3.0	1.0, 4.5	24	3.0	2.25, 4.75
Dyspnea or fear of worsening dyspnea	69	3.0	1.0, 5.0	24	1.5	1.0, 4.0
Mental confusion or fear of mental confusion	67	3.0	1.0, 4.0	27	2.0	1.0, 4.0
Witnessed bad deaths	44	2.0	1.0, 3.75	21	2.0	1.0, 4.0

Table 3. **Reasons for requesting a lethal prescription among hospice clients who received one * (cont)**

Reason client wanted a lethal prescription	**Hospice Nurses (N = 82)**			**Social Workers (N = 38)**		
	No. of Responses†	**Median Score‡**	**IQR§**	**No. of Responses†**	**Median Score‡**	**IQR§**
Perceived self as financial drain to others or fear of becoming a financial drain	60	2.0	1.0, 3.0	23	2.0	1.0, 4.0
Depression or other psychiatric disorder	59	2.0	1.0, 3.0	25	1.0	1.0, 2.5
Nausea or fear of worsening nausea	67	2.0	1.0, 3.0	23	1.0	1.0, 3.0
Lack of social support	65	1.0	1.0, 2.0	26	1.0	1.0, 3.0

*Respondents asked to mark only those reasons that reflected actual conversations with the client or family.

†Some respondents marked "Did not know/did not discuss," or left blank.

‡1 to 5 scale, with 1 = "Not at all important in decision to request a lethal prescription" and 5 = "Very important in decision to request a lethal prescription."

§IQR = interquartile range

Table 4. Attitudes of families of patients who received a lethal prescription

	Hospice Nurses (N = 82)	Hospice Social Workers (N = 38)
Families' awareness of patients' request for a lethal prescription		
All knew	70 (85%)	28 (74%)
One or two knew	11 (13%)	6 (16%)
Patient kept intentions from family	0	0
No family to notify	1 (1%)	2 (5%)
Missing	0	2 (5%)
Did the hospice practitioner discuss the request for a lethal prescription with family?		
Yes	63 (76%)	29 (76%)
No	19 (23%)	7 (18%)
Missing	0	2 (5%)
Was family accepting of patient's preference for a lethal prescription?		
All accepting	36 (44%)	14 (37%)
Most accepting	38 (46%)	17 (45%)
Many opposed	3 (4%)	1 (3%)

Table 4. Attitudes of families of patients who received a lethal prescription (cont)

	Hospice Nurses (N = 82)	**Hospice Social Workers (N = 38)**
All opposed	1 (1%)	1 (3%)
Unsure, missing	4 (5%)	5 (13%)
Was the patient's decision about assisted suicide influenced by family?		
Not at all	55 (67%)	25 (66%)
Somewhat	22 (27%)	8 (21%)
A great deal	3 (4%)	1 (3%)
Missing	2 (2%)	4 (11%)

Figure 1. Hospice Nurses' (N = 82) Views of Differences Between Clients Who Receive a Lethal Prescription and Other Hospice Clients

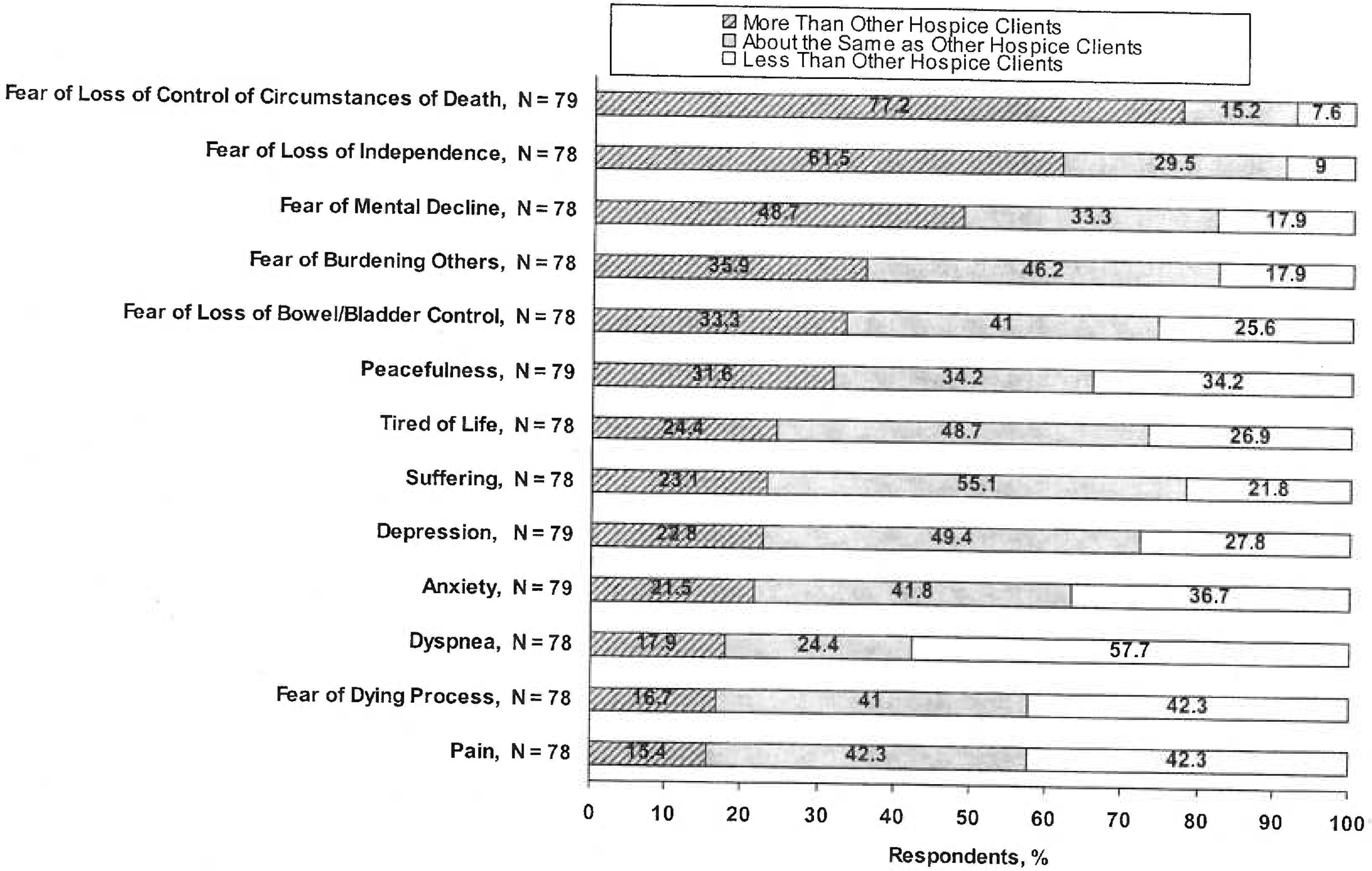
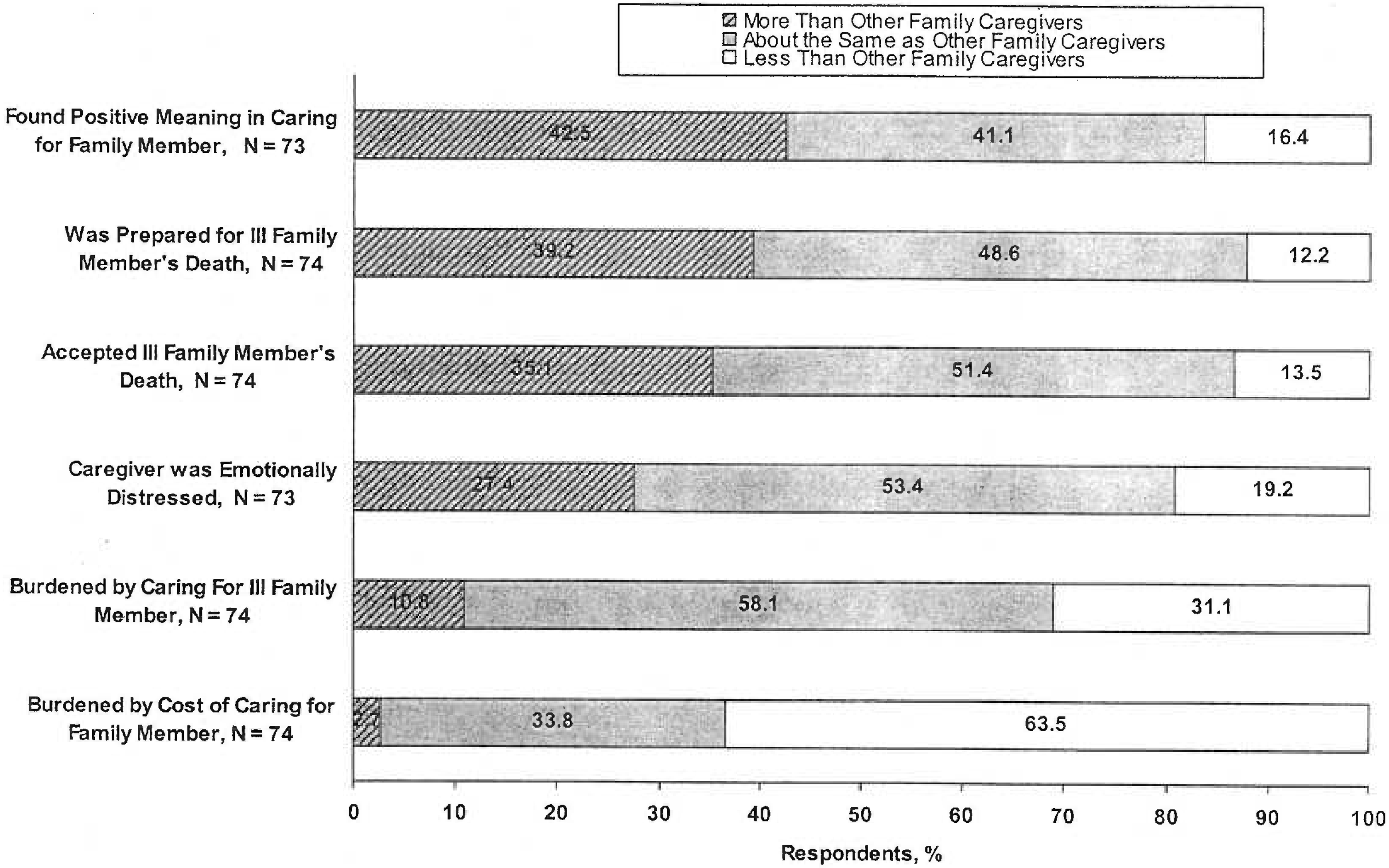


Figure 2. Hospice Nurses' (N = 82) Views of Differences Between Family Caregivers of Clients Who Receive a Lethal Prescription and Other Hospice Clients' Family Caregivers



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Appendix

Copy of Survey Instrument

Four phrases are used throughout the questionnaire and are defined as follows:

Physician-assisted suicide is defined as death that results from a legally prescribed lethal dose of medicine for a competent, terminally-ill patient to self-administer with the primary intention of ending his/her life.

The Oregon Death with Dignity Act legalizes the practice of physician-assisted suicide for competent Oregonians who are expected to live less than 6 months. This law was passed in 1994 and enacted in November 1997.

A lethal prescription is a prescription for a medication to be used for the purpose of causing death. Explicit requests are requests from a client to a physician, nurse, or social worker for a lethal dose of medicine to be used to end life as set forth in the Oregon Death with Dignity Act.

Voluntary refusal of food and fluids describes an action by a client who voluntarily and deliberately stops all food and fluids with the primary intention of hastening death. This does not include stopping food and fluids for other reasons in the course of a terminal illness, such as loss of appetite or inability to eat or drink because of disease.

Part A

Information about you:

A1. Today's date: ____________________

A2. What is your age in years? ____________

A3. How many years have you worked in hospice? _____________

A4. Your sex:
- ☐ Male
- ☐ Female

A5. What is your profession?
- ☐ Nurse
- ☐ Social Worker
- ☐ Other → Please specify: ____

A6. Hospice position: **(Mark all that apply.)**
- ☐ Manager/Director/Administrator
- ☐ Direct care staff

A7. Is your hospice affiliated with a religious organization?
- ☐ Yes
- ☐ No

A8. What is the population of the area in which your work is located?

- ☐ Rural area or small city/town (population under 25,000)
- ☐ Medium-size city (population 25,000-250,000)
- ☐ Large city (population over 250,000) or suburb near a large city

A9. What is your current religious affiliation?

- ☐ Catholic
- ☐ Jewish
- ☐ Muslim
- ☐ Protestant → If Protestant, what branch or denomination? ____________________
- ☐ None
- ☐ Other → Please specify: ____

A10. Fill in the box of the <u>one number</u> which reflects the importance of religion in your life, where 0 means religion is not important and 10 means religion is very important.

	0	1	2	3	4	5	6	7	8	9	10	
religion not important to me	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	religion very important to me

A11. Fill in the box of the <u>one number</u> which reflects the importance of spirituality in your life, where 0 means spirituality is not important and 10 means spirituality is very important.

	0	1	2	3	4	5	6	7	8	9	10	
spirituality not important to me	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	spirituality very important to me

Your views about death-hastening acts:

Please mark the single best answer.

A12. Do you currently support or oppose the Oregon Death with Dignity Act?

- ☐ Strongly support
- ☐ Support
- ☐ Neither support nor oppose
- ☐ Oppose
- ☐ Strongly oppose

A13. Since 1994, when Oregon voters first passed this ballot measure, has your support for or opposition to the Oregon Death with Dignity Act changed?

- ☐ Much more supportive
- ☐ Somewhat more supportive
- ☐ No change
- ☐ Somewhat more opposed
- ☐ Much more opposed

If your position has changed, why? ____

____

____

A14. If a hospice client for whom you cared and who met the requirements of the Oregon Death with Dignity Act requested a lethal prescription from a physician, how would you respond?

☐ Actively oppose the client's choice in all cases
☐ Actively oppose the client's choice in most cases
☐ Neither support nor oppose the client's choice
☐ Actively support the client's choice in most cases
☐ Actively support the client's choice in all cases

A15. If a hospice client for whom you cared and who met the requirements of the Oregon Death with Dignity Act requested a lethal prescription from a physician, how would you respond?

☐ Continue to follow the client until death or discharge
☐ Transfer the client to another provider at the time of the client's request
☐ Transfer the client to another provider at the time the client actually received the prescription
☐ Other → Please specify: ____

A16. If a hospice client for whom you cared decided to <u>deliberately hasten death</u> by voluntary refusal of food and fluids, how would you respond?

☐ Actively oppose the client's choice in all cases
☐ Actively oppose the client's choice in most cases
☐ Neither support nor oppose the client's choice
☐ Actively support the client's choice in most cases
☐ Actively support the client's choice in all cases

Please indicate your disagreement or agreement with each of the following statements by marking the number that corresponds with your answer.

	Completely Disagree	Generally Disagree	Neither Agree nor Disagree	Generally Agree	Completely Agree
A17. The writing of a lethal prescription by a physician for a patient under the Oregon Death with Dignity Act is immoral and/or unethical.	1	2	3	4	5
A18. Terminally-ill patients should have the option of ending their lives by physician-assisted suicide if physical suffering becomes unbearable.	1	2	3	4	5
A19. Physician-assisted suicide has no role in terminal care.	1	2	3	4	5
A20. Terminally-ill patients should have the option of ending their lives by physician-assisted suicide if psychological or spiritual suffering becomes unbearable.	1	2	3	4	5

Only answer questions in Part B if you have had a client who has explicitly requested a lethal prescription from a physician and is now deceased.

Part B

In the following pages, please fill out information to the best of your recollection about <u>the one most recent client</u> who has made an explicit request to a physician for a lethal prescription since November 1997 <u>and</u> who is now deceased.

B1. Did this person receive a prescription for a lethal medicine <u>from a physician</u>?

- ☐ Yes, received one (**Check the <u>one</u> answer below that best describes the outcome.**)
  - ☐ Received and died from self-administering the lethal prescription
  - ☐ Received, but died from other causes
  - ☐ Received and died, but I am unsure if the client took the lethal prescription
- ☐ No, did not receive a lethal prescription (**Please check all the boxes below that apply.**)
  - ☐ Client could not find a willing physician
  - ☐ The client did not meet criteria under Oregon law
    Why didn't the client meet criteria? ______________________
    ____
  - ☐ The client changed his/her mind and no longer wanted to suicide by lethal prescription under the Oregon Death with Dignity Act
  - ☐ The client died before completing the requirements of the Oregon Death with Dignity Act
  - ☐ The client suicided or attempted suicide by means other than physician-assisted suicide
    How did this client suicide or attempt suicide? ______________
    ____
  - ☐ The client chose to hasten death via voluntary discontinuation of food and fluids (**Go to Part C, page 19**)
  - ☐ Other → Please describe: ______________________
- ☐ Unsure if received a lethal prescription

Answer these following questions about the client at the time closest to when he/she initially made the request for a lethal prescription.

B2. Client's age in years: ______________

B3. Client's marital status:

- ☐ Married/Living as married
- ☐ Divorced/Separated/Widowed/Never married
- ☐ Don't know

B4. Client's sex:

- ☐ Male
- ☐ Female

B5. Size of community in which client resided:
- ☐ Rural area or small city/town (under 25,000)
- ☐ Medium-size city (25,000-250,000)
- ☐ Large city (over 250,000) or suburb near a large city

B6. What were the client's terminal diagnoses? **(Mark all that apply.)**
- ☐ Malignancy
- ☐ End-stage cardiopulmonary disease
- ☐ Neurologic disease
- ☐ Other → Indicate disease: ____________________

B7. Were the client's family or significant others aware of the client's request?
- ☐ Yes, apparently all knew
- ☐ Yes, one or two persons knew
- ☐ No, kept intentions from family and significant others
- ☐ No, no family or significant others to notify
- ☐ Don't know

B8. Did you personally speak to a family member or significant other about this client's request?
- ☐ Yes
- ☐ No

B9. Was the family accepting of the client's desire to pursue physician-assisted suicide?
- ☐ Yes, all were accepting
- ☐ Yes, most were accepting
- ☐ No, many were opposed
- ☐ No, all were opposed
- ☐ Don't know

B10. To what extent was the client's decision-making about assisted suicide influenced by his/her family?
- ☐ Not at all
- ☐ Somewhat
- ☐ A great deal

B11. Did you discuss the client's request with any coworkers?
- ☐ No, did not discuss
- ☐ Yes, discussed with: **(Fill in all that apply.)**
  - ☐ Hospice social worker
  - ☐ Client's physician
  - ☐ Other hospice providers
  - ☐ Interdisciplinary team at care conference

B12. Was the client evaluated by any mental health professional?
- ☐ No
- ☐ Yes, client was evaluated by: **(Fill in all that apply.)**
  - ☐ Hospice social worker
  - ☐ Other social worker
  - ☐ Psychiatrist, psychologist or mental health nurse practitioner

This section will assist us in exploring the reason why a client might request a lethal prescription. Mark whether the symptom or fear of it worsening was the reason for the request. Mark only those that reflect actual conversations with the client or family. (Mark all that apply.)

	Not at all important in decision to request a lethal prescription 1	2	3	**Very important in decision to request a lethal prescription** 4	5	**Do not know / Did not discuss**
B13. Pain or fear of worsening pain	1	2	3	4	5	☐
B14. Depression or other psychiatric disorder	1	2	3	4	5	☐
B15. Nausea or fear of worsening nausea	1	2	3	4	5	☐
B16. Dyspnea (air hunger) or fear of worsening dyspnea	1	2	3	4	5	☐
B17. Mental confusion or fear of worsening confusion	1	2	3	4	5	☐
B18. Loss of bowel or bladder function or fear of loss of bowel or bladder function	1	2	3	4	5	☐
B19. Fatigue/lack of energy or fear of fatigue/lack of energy	1	2	3	4	5	☐
B20. Perceived self as a burden to others or fear of becoming a burden	1	2	3	4	5	☐
B21. Loss of dignity or fear of loss of dignity	1	2	3	4	5	☐
B22. Loss of independence or fear of loss of independence	1	2	3	4	5	☐
B23. Perceived self as financial drain to others or fear of becoming a financial drain	1	2	3	4	5	☐
B24. Poor quality of life or fear of poor quality of life	1	2	3	4	5	☐
B25. Lack of social support	1	2	3	4	5	☐

	Not at all important in decision to request a lethal prescription			**Very important in decision to request a lethal prescription**		**Do not know / Did not discuss**
	1	**2**	**3**	**4**	**5**	
B26. Inability to perform personal care or fear of becoming unable to perform personal care	1	2	3	4	5	☐
B27. Could not pursue previously pleasurable activities	1	2	3	4	5	☐
B28. Ready to die	1	2	3	4	5	☐
B29. Wanted to control circumstances of death	1	2	3	4	5	☐
B30. Wanted to die at home	1	2	3	4	5	☐
B31. Saw continued existence as pointless	1	2	3	4	5	☐
B32. Life tasks completed	1	2	3	4	5	☐
B33. Had witnessed other "bad deaths"	1	2	3	4	5	☐

B34. Did the client discuss his/her fears about dying?

☐ Yes

If yes, what were the client's major fears? ______________________________

____

____

☐ Discussed, but had no fears
☐ No, did not discuss
☐ I don't remember

B35. Was it easy or difficult to develop a helping relationship with this client? Zero equals "very difficult to develop a helping relationship" and 9 equals "very easy to develop a helping relationship."

Very difficult to develop a helping relationship	0	1	2	3	4	5	6	7	8	9	Very easy to develop a helping relationship
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

B36. Did he/she have an opportunity to complete tasks that were important prior to his/her death?

☐ Yes, <u>most</u> important tasks were completed
☐ Yes, <u>some</u> important tasks were completed
☐ No, <u>no</u> important tasks were completed
☐ Unsure

B37. Did he/she have the chance to say good-bye to loved ones?

☐ Yes, to <u>most</u> loved ones
☐ Yes, to a <u>few</u> loved ones
☐ No, to <u>no</u> loved ones
☐ Unsure

B38. Overall, how confident were you that you could facilitate a "good death" from the client's point of view without assisted suicide? Zero equals "not confident" and 9 equals "very confident."

	0	1	2	3	4	5	6	7	8	9	
Not confident	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Very confident

B39. Please rate the client's overall peacefulness in the <u>2 weeks</u> before death where 0 equals "very much at peace" and 9 equals "not at all at peace."

	0	1	2	3	4	5	6	7	8	9	
Very much at peace	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Not at all at peace

B40. Please rate the client's overall suffering in the <u>2 weeks</u> before death where 0 equals "no suffering at all" and 9 equals "severe, unremitting suffering."

	0	1	2	3	4	5	6	7	8	9	
No suffering at all	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Severe, unremitting suffering

B41. Please rate the client's overall level of pain in the <u>2 weeks</u> before death where 0 equals "no pain at all" and 9 equals "severe, unremitting pain."

	0	1	2	3	4	5	6	7	8	9	
No pain at all	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Severe, unremitting pain

B42. Overall would you rate this as a "good death" or a "bad death" where 0 equals "very bad death" and 9 equals "very good death"?

	0	1	2	3	4	5	6	7	8	9	
Very bad death	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Very good death

Compare this client to other hospice clients, and mark how the following characteristics compared, on average, to other hospice clients for whom you have cared.

B43. Pain

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B44. Low mood/depression

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B45. Dyspnea

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B46. Anxiety

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B47. Fear of loss of bowel/ bladder control

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B48. Fear of mental decline

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B49. Fear of burdening others

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B50. Fear of loss of independence

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B51. Fear of loss of control of circumstances of death

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B52. Fear of dying process

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B53. Tired of life

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B54. Suffering

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

B55. Peacefulness

1	2	3	4	5
Much less compared to other hospice clients		About the same as other hospice clients		Much more compared to other hospice clients

Compare this client's <u>most important family caregiver</u> to other hospice family caregivers and mark how the following characteristics compared, on average, to other family caregivers with whom you have worked.
Mark here if no family caregiver ☐ and go to question B62.

B56. Felt burdened by caring for ill family member

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B57. Felt burdened by the cost of care for this ill family member

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B58. Found positive meaning in caring for this family member

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B59. Accepted ill family member's death

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B60. Was prepared for ill family member's death

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B61. Was emotionally distressed

1	2	3	4	5
Much less compared to other family caregivers		About the same as other family caregivers		Much more compared to other family caregivers

B62. Since November 1997, have you cared for any clients who voluntarily chose to deliberately hasten death by refusal of food and fluids? (Please include clients who may have changed their mind and resumed eating or drinking, or died from other causes.)

☐ Yes → *Please go to Part C, next page*
☐ No → *Please go to Part D, page 27*