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Attitudes and experiences of Oregon hospice nurses and social workers regarding assisted suicide*

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Background: When the Oregon Death with Dignity Act (ODDA) legalizing physician-assisted suicide was enacted into law in 1997, Oregon hospice clinicians were uncertain how involved they would be with patients who wanted this option. However, 86% of the 171 persons in Oregon who have died by lethal prescription were enrolled in hospice programmes. **Method:** A mailed questionnaire was sent to all hospice nurses and social workers in Oregon in 2001 ($n=573$) to assess their attitudes about legalized assisted suicide and interactions with patients concerning this issue. Responses from 306 nurses and 85 social workers are included in this report. **Findings:** Almost two-thirds of respondents reported that at least one patient had discussed assisted suicide as a potential option in the past year. Social workers were generally more supportive of both the ODDA and of patients choosing assisted suicide compared to nurses. Twenty-two per cent of all respondents were not comfortable discussing assisted suicide with patients. Ninety-five per cent of both groups, however, favoured hospice policies that would allow a patient to choose assisted suicide while enrolled in hospice and allow hospice clinicians to continue to provide care. **Interpretations:** Nurses and social workers in hospices and other settings can expect to encounter patient questions about physician-assisted suicide, whether legalized or not, and must be prepared to have these discussions. Most hospice professionals in Oregon do not believe that assisted suicide and hospice enrolment are mutually exclusive alternatives. *Palliative Medicine* 2004; **18:** 685–691

Key words: attitudes; euthanasia; hospice; nurses; physician-assisted suicide; social workers

Introduction

When the Oregon Death with Dignity Act (ODDA)[1] legalizing physician-assisted suicide was enacted into law in 1997, Oregon hospices and hospice professionals were uncertain how involved they would be with patients who wanted this option at the end of life; hospice had been viewed as an alternative to assisted suicide. The official position of both the National and the Oregon Hospice Associations, before and after the passage of ODDA, was that 'death should neither be hastened nor prolonged';[2] Oregon hospices had either no policies on assisted suicide or policies in opposition to the practice.[3] However, between 1998 and 2003, the Oregon Health Division reported that 86% of the 171 persons in Oregon who died by lethal prescription under the ODDA had been enrolled in hospice programmes.[4] Studies of attitudes about assisted suicide may inform the wider debate called for by the European Association of Palliative Care as several new approaches to euthanasia and assisted suicide emerge in European countries.[5]

In 2001, we sent surveys to all hospice nurses and social workers in Oregon, asking about their attitudes and experiences with assisted suicide. In a previous paper, we reported the experiences of the 82 Oregon hospice nurses and social workers who cared for a patient who actually received a lethal prescription under the ODDA.[6] These respondents reported that the most important reason for the request was a desire for control over the circumstances of death. The least important reasons included depression, lack of social support and fear of being a financial drain on family members. This paper reports on *all* nurse and social worker respondents to the survey, their attitudes about assisted suicide and the ODDA, their views on the role of hospice for assisted suicide patients, and their interactions with patients about this issue.

*The views expressed in this article are those of the authors and do not necessarily represent the views of Oregon Health & Science University, the US Department of Veterans Affairs, the Oregon Hospice Association, the Greenwall Foundation or the US Government.

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Method

Study setting and design

Oregon has 52 hospices; one is an in-patient facility, one is a prison hospice, and the remaining 50 are in-home hospices. Hospice services are widely available in all geographic areas of Oregon; over 10 000 people per year die in hospice.[7] The percentage of all deaths in Oregon that occur in hospice is currently 37%, one of the highest rates in the USA.[7]

This study consisted of a mailed, self-administered questionnaire that was sent to hospice nurses and social workers in all 50 Medicare-certified in-home hospice programmes in Oregon, as well as one programme each in southern Washington and Idaho that provide care for Oregon residents. All hospice programmes participated in the study and submitted the names of or delivered questionnaires to all 573 employees.

Questionnaire

The questionnaire has been previously described.[6] Demographic items used for this analysis included age, gender, profession (nurse, social worker), years of hospice work, population of the hospice service area, religious affiliation of the hospice and religious affiliation of the respondent. The importance of religion and spirituality to the respondent were each rated on a Likert scale ranging from 0 (not important) to 10 (very important).

Attitudes were measured with several single items and two scales. Single items addressed respondents' support or opposition to the ODDA and assisted suicide, change in support of ODDA, personal response to patient requests for assisted suicide, comfort in discussing assisted suicide with patients and with other providers, and support or opposition to hospice policies on assisted suicide. Four items addressed respondents' perceptions of patients' reactions to respondents' personal position and hospice policies on assisted suicide. We did not ask respondents if they had actually helped a patient ingest a lethal prescription or if they would do so, because it is explicitly prohibited under ODDA;[1] patients must ingest the prescription unaided by others. Lethal injection and euthanasia are also specifically prohibited.

The 4-item Assisted Suicide Attitude Scale was developed for this study and had a response range of 1 (completely disagree) to 5 (completely agree). It asked whether respondents: 1) viewed assisted suicide as immoral or unethical; 2) whether it has a role in hospice; 3) whether it should be an option for physical suffering; and 4) whether it should be an option for psychological or spiritual suffering. High scores indicated a higher level of support for assisted suicide. The 5-item Comfort Discussing Assisted Suicide Scale was also developed for this study. It asked respondents how comfortable they were: 1) discussing assisted suicide with patients, 2) discussing it with co-workers, and 3) discussing it with supervisors; 4) how comfortable they were asking for consultation from co-workers; and 5) how comfortable they were asking for consultation from supervisors (1 = not at all, 4 = a great deal). High scores indicated a greater comfort in discussing assisted suicide. Scale scores for each scale were computed as the average of items for those who answered at least three of the scale's items. Those who answered fewer than three items were assigned a missing value ($n = 2$). Cronbach's alpha for the Assisted Suicide Attitude Scale was 0.90 and 0.75 for the Comfort Discussing Assisted Suicide Scale.

The questionnaires were mailed between July and September 2001 and included a cheque for $10. Because the questionnaire was anonymous, the institutional review board at the Portland Veterans Affairs Medical Center waived the requirement for obtaining written informed consent.

Sample

Of the original 573 potential respondents, 28 were excluded because they no longer worked at the hospice agency or did not care for patients in Oregon. Of the remaining 545, 397 returned the questionnaire; 306 of 429 nurses (71%) and 91 of 116 social workers (78%). Of the 91 respondents who were identified as social workers by their agencies, six self-identified as counsellors with non-social work degrees and were dropped from the analysis. Demographics of the sample are summarized in Table 1.

Statistical analysis

Summary statistics are presented as frequencies, proportions, means and standard deviations. Chi-square test was used to compare nurses and social workers on categorical variables and t-tests were used to test differences on continuous variables. Hierarchical regression models were employed to identify the predictors of respondents' attitudes on assisted suicide. The alpha was set at 0.05. All tests were two-tailed.

Results

As previously reported, 179 (45%) respondents had cared for a patient who had explicitly requested assisted suicide under the ODDA.[6] In the current analysis, almost two-thirds of the entire sample ($n = 244$, 62.4%) reported that they had cared for at least one patient with whom they discussed assisted suicide as a potential option in the past year. The number of patients per respondent who discussed assisted suicide ranged from 1 to 30, with a median of 1. More than half of respondents ($n = 217$, 55.5%) reported that they had cared for at least one patient who expressed an interest in actually pursuing assisted suicide in the last year with a range of 1–10

Table 1 Characteristics of hospice nurses and social worker respondents ($n=391$)

Characteristic	Nurses ($n=306$) *M* (SD)	Social workers ($n=85$) *M* (SD)	P value
Age in years[a]	49.3 (9.4)	48.9 (8.7)	N.S.
Hospice employment in years[d]	7.0 (5.2)	6.4 (5.3)	N.S.
Importance of religion[b]	6.6 (3.6)	5.0 (3.7)	0.00
Importance of spirituality[b]	9.3 (1.6)	9.1 (1.6)	N.S.
	n (%)	*n* (%)	P value
Gender – no. (%)[c]			
Female	290 (95)	64 (78)	0.00
Male	16 (5)	18 (22)	
Hospice agency is affiliated with religious organization[a]	73 (24)	16 (20)	N.S.
Type and size of area served by hospice – no. (%)[d]			
Rural area or small town, <25 000 population	135 (44)	32 (41)	N.S.
Medium-sized city, 25 000–250 000 population	104 (34)	27 (34)	
Large city, >250 000 population	65 (22)	20 (25)	
Religious affiliation of respondents[a]			
Catholic	40 (13)	9 (11)	0.01
Jewish	2 (1)	3 (5)	
Protestant	86 (28)	23 (28)	
None	56 (19)	20 (23)	
Christian other	84 (28)	12 (14)	
Other non-Christian	26 (9)	13 (16)	
Other undefined	9 (3)	3 (3)	

[a]Missing = 5.
[b]Missing = 2.
[c]Missing = 3.
[d]Missing = 8.
Importance of religion and spirituality – 0 = not at all important, 10 = very important.

patients and a median of 1. Of these, 81 (37.3%) attempted to facilitate a patient's access to a legal lethal prescription.

Attitudes on assisted suicide

Social workers reported a higher level of support for assisted suicide on two of the four single attitude items. They were more supportive of the ODDA than nurses and reported a higher level of support for patients who might request a lethal prescription (Figure 1). On the Assisted Suicide Attitude Scale, social workers also reported higher scores ($M=3.9$, SD = 1.0) than nurses ($M=3.4$, SD = 1.3), t (384) = −3.5, P = 0.00. An overwhelming proportion (95%) of the entire sample, however, believed that their hospice agency should either be supportive of a patient's choice for assisted suicide or remain neutral (i.e., neither support nor oppose), with no difference between nurses and social workers on this item.

Response to patients

Only two social workers (2%), but 36 nurses (12%) would transfer care of a patient who received a lethal prescription to another hospice clinician (P = 0.01)

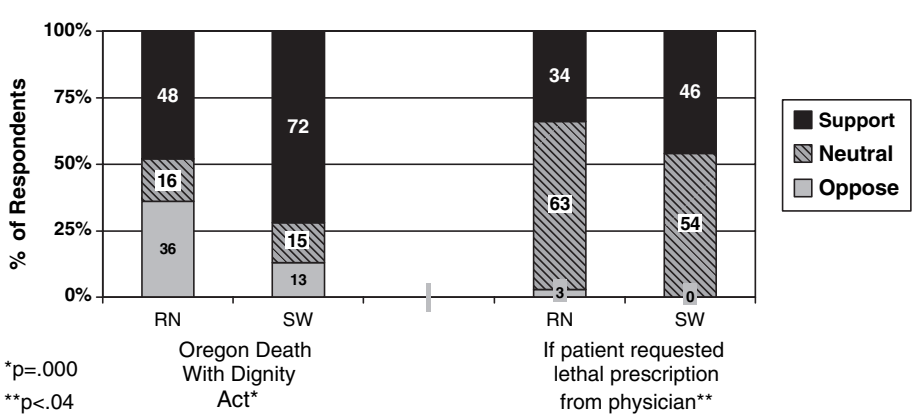

Figure 1 Support and opposition of nurses and social workers about assisted suicide.

(Table 2). There was no difference between the two groups in what they thought the hospice agency's response to patients who request assisted suicide should be, with a very high proportion (95%) of both groups endorsing that hospice agencies should continue to care for these patients. Likewise, there was no difference between the groups in their response to a patient's request that they be present at the death, with about one-third of each group agreeing in most cases. Very small numbers of both groups (nurses = 10, social workers = 1) had actually attended an assisted suicide death since the law was passed.

Discussions of assisted suicide with patients and other providers

Fifty-nine (15%) respondents reported that they themselves had initiated a discussion about assisted suicide with a patient and 89 (23.3%) had *wanted* to initiate a discussion, but thought they could not. In addition, 77 (19.7%) reported that physicians, caregivers or others had brought to their attention that a patient was interested in assisted suicide, but the patient did not bring it up with the respondent. Although almost two-thirds of respondents reported that at least one patient had discussed assisted suicide in the past year, 86 (22%) were not at all comfortable or only a little comfortable discussing assisted suicide with patients; social workers were more comfortable than nurses. There were no differences between nurses and social workers in their comfort in discussing assisted suicide with co-workers and supervisors, or in seeking their consultation.

Perceptions of patients' reactions to respondent position and hospice policies on assisted suicide

For the overall sample, 78 respondents (20%) reported that one or more patients were more positive or comfortable about their care after knowing the respondent's personal position on assisted suicide, and 92 (23.5%) reported that patients were more positive or comfortable about their care after knowing the hospice agency's policies. Only nine respondents (2.3%) reported that one or more patients was concerned or upset because of the respondent's personal opinion on assisted suicide or the ODDA, and 49 (12.5%) reported one or more patients was concerned or upset because of the hospice agency's policies. The difference between nurses and social workers on these items was not significant.

Determinants of attitude and comfort discussing assisted suicide

In the bivariate analysis, attitude on assisted suicide using the Attitude about Assisted Suicide Scale was not significantly correlated with any demographic variable with the exception of profession. It was also significantly correlated with the importance of religion. How religion and profession predicted attitudes was modelled through hierarchical multiple regression analyses. We entered importance of religion (0–10) at Step 1, profession at Step 2, and the interaction between the importance of religion and profession at Step 3. At Step 1, the importance of religion explained 24.4% of the variance in assisted suicide attitudes ($P < 0.001$), with those viewing religion as less important expressing more supportive attitudes. In Step 2 profession explained an

Table 2 Hospice nurses and social workers' responses to patients who request assisted suicide

Item	Nurses *n* (%)	Social workers *n* (%)	P value
If your hospice patient requested a lethal prescription from a physician, how would you respond?[a]			
Continue to follow until death or discharge from hospice	255 (84)	79 (98)	
Transfer the patient to another provider	36 (12)	2 (2)	0.01
Other	14 (4)	0	
What should hospice stance toward patients who request legal assisted suicide?[a]			
Discharge patient, discontinue care	17 (6)	1 (1)	N.S.
Continue care	286 (94)	82 (99)	
How would you respond to patient's request that you be present at the death?[b]			
In most cases, I would agree	94 (31)	26 (34)	N.S.
I am as likely to decline as to agree	19 (6)	6 (7)	
In most cases, I would decline to be present	154 (51)	40 (49)	
Not sure	37 (12)	8 (10)	
Have you attended an assisted suicide death since 1997?[c]			
Yes	10 (3)	1 (1)	N.S.

[a]Missing = 4.
[b]Missing = 3.
[c]Missing = 2.

additional 0.7% of the variance in assisted suicide attitudes ($P = 0.06$), with a trend for social workers to report more supportive attitudes. In Step 3 the interaction between importance of religion and profession explained an additional 1.4% of the variance ($P = 0.007$).

In a second bivariate analysis, comfort discussing assisted suicide using the Comfort Discussing Assisted Suicide Scale, was not correlated with any of the demographic variables with the exception of the religious affiliation of the hospice agency, which was low but significant ($r = 0.18$, $P < 0.001$). Respondents from religious-affiliated hospices reported less comfort in discussing assisted suicide. This scale also was not associated with the Attitudes about Assisted Suicide Scale.

Discussion

The results of this study help to inform the debate about whether euthanasia and assisted suicide can be part of palliative and hospice care.[5,8–10] Despite the presumption that hospice would be a mutually exclusive alternative to assisted suicide under the ODDA, implementation of the law has resulted in their coexistence. A large majority of hospice nurse and social worker respondents were asked about assisted suicide by patients, many facilitated patients' decision-making process, and some attended a suicide death. Large proportions of respondents, including many who were opposed to the ODDA, reported they would continue to care for a patient who requested a lethal prescription. An overwhelming proportion of respondents favoured hospice policies that either support a patient's choice for or remain neutral about assisted suicide, thus permitting them to care for these patients. Less than 5% of respondents thought that patients who wanted assisted suicide should be discharged from hospice.

Several arguments can be made in support of euthanasia and assisted suicide as justifiable within the context of good palliative care.[8] First, patients who want assisted suicide need not be denied the benefit of symptom management, nor the spiritual, emotional and family support available to other terminally ill patients. Secondly, anxiety may be diminished for some patients just by knowing that a lethal prescription is available should they need it, even though they may never use it. It may be that within the context of compassionate palliative care, the vast majority of requests disappear after some time, as some have suggested.[8,11] Of 58 Oregon patients who received lethal prescriptions in 2002, 16 died without taking the prescription and six patients were still alive at the end of the year.[4] Thirdly, patients who want assisted suicide under the Oregon law can take the lethal prescription in their own homes, in contrast to the Dutch system, where hospice care is provided in institutions, and patients who want a lethal prescription must be transferred to a setting where euthanasia is allowed.[8]

These results raise questions about the position of the Ethics Task Force of the European Association of Palliative Care (EAPC),[5] specifically, position #4 which states 'the provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care' (p. 99). We agree with Campbell and Huxtable that 'the position statement's attempt to isolate palliative care practice from the possibility of euthanasia (and we would add assisted suicide) fails to work, both theoretically and clinically'[12] (p. 181). Clinically it fails because assisted suicide involves much more than procuring and administering lethal drugs. It involves a complex process in which patients seek information about many aspects of dying (including assisted suicide) within a trusted relationship with hospice professionals, so that they can make decisions about how to live their final days. When assisted suicide is legal, questions about it naturally arise; when such patients are enrolled in hospice programmes, hospice professionals are the recipients of such questions, as our study demonstrates. Some have suggested that the multidisciplinary model of care practiced in hospice is the best model to address legal requests for assistance in dying because no single health care profession has all the skills needed to assure that patients receive the best care.[13]

Although more than three-fifths of respondents discussed assisted suicide with at least one patient, almost one-quarter were not comfortable doing so. Education, training and support are warranted to improve hospice professionals' communication about assisted suicide without imposing their personal views (either in support or opposition). Guidelines are needed to assure that hospice professionals systematically address all treatable problems to reduce the chance that assisted suicide is chosen unnecessarily. Such changes would be especially important if similar laws are passed in other jurisdictions.

Comparison of attitudes on assisted suicide with other groups

Nurses' attitudes on the ODDA in this study are similar to those of Oregon physicians who were surveyed in 1999.[14] In that study, 32% of physicians were opposed to the ODDA, 51% supported it and 17% were neutral. Likewise, physicians reported similar changes in their views of assisted suicide as did the nurses in this study; 13% were more supportive and 7% were more opposed. On the other hand, a much smaller proportion of social workers were opposed to the ODDA compared with physicians and nurses, and a greater proportion reported increased support since 1994 (Table 3).

Table 3 Proportion of physicians, nurses, social workers in support of and opposition to ODDA

	Physicians (%)	Nurses (%)	Social workers (%)
Support ODDA	51	48	72
Oppose ODDA	32	36	13
Neutral on ODDA	17	16	15
More supportive since 1994	13	16	24
More opposed since 1994	7	9	5

Predictors of attitudes on assisted suicide

Similar to other studies, we found that increasing strength of religious beliefs was associated with greater opposition to assisted suicide.[15–17] Profession as a predictor of attitudes is a new finding and reflects a difference in tone and emphasis in the nurse and social worker professional organizations' codes of ethics and position statements on assisted suicide. The American Nurses Association's (ANA) begins its position statement with a patient-centred emphasis, stating 'the central axiom that directs the profession is respect for persons'.[18] At the same time, however, the statement contains several strong oppositional wordings (e.g., 'participation in assisted suicide is a violation of the Code for Nurses').

In contrast, the Policy Statement Concerning End-of-life Decisions of the US National Association of Social Workers (NASW)[19] views client self-determination as the primary guiding principle of social work practice. It states that 'assisted suicide is one of many options for persons with a terminal condition' and that end-of-life decisions should be 'based on client self-determination'. In addition, the NASW 'does not take a position concerning the morality of end-of-life decisions, but affirms the right of the individual to determine the level of his or her care.'

In response to the need for guidance in assisted suicide situations, the Oregon Nurses Association has issued a Whitepaper on the Oregon Death with Dignity Act.[20] For nurses who are supportive of the ODDA, guidelines for participation include exploring reasons for the request, determining whether the patient is depressed, explaining the ODDA, discussing and exploring options with regard to end of life decisions, and being present during ingestion of the lethal drug and during the death. Guidelines for nurses who are opposed to assisted suicide include conscientiously objecting to involvement in care and transferring care to another clinician after assuring the patient's safety. Guidelines for both groups include maintaining confidentiality of the patient and family.

Ethical conflicts

Although we did not specifically ask about respondents' ethical conflicts, several potential conflicts may occur. One is the conflict between not participating in hastening death and abandoning patients.[21,22] Our results demonstrate that respondents, even those who do not philosophically support assisted suicide, would choose to continue caring for patients requesting assisted suicide. Ethical conflict may also be experienced by hospice clinicians who are opposed to assisted suicide and wish to transfer care of a patient to another clinician, but are unable to due to small agency size or other organizational constraints. Similarly, hospice clinicians who are supportive but work in hospice agencies that discourage assisted suicide (e.g., some religious-affiliated agencies) may also experience ethical conflict. Conflict may develop if the clinician is asked to assist with the suicide by helping a patient to ingest the lethal prescription when he or she is unable. Several studies in other US states have reported that both nurses and social workers either have given a lethal dose, have witnessed an assisted suicide or would be willing to participate in an assisted suicide if asked, even though these actions are illegal.[15,23–27] Similarly, in the Netherlands, 21% of physician specialists and 3% of nursing home physicians reported that nurses administered the lethal drug for patients who died by euthanasia, although it is illegal for nurses to do so.[28] Further study of these potential conflicts is warranted.

Limitations

As with all mailed surveys, the attitudes of nonresponders are not known. Specifically, did they fail to respond because they disapproved of assisted suicide or had a bad experience with it? In addition, questions that rely on memory, as some in the questionnaire did, may be difficult to complete accurately. We did not obtain information about the nature and extent of the discussions between patients and hospice professionals, nor the circumstances of patients who carried out an assisted suicide vis-à-vis those who only asked for information, but did not pursue it or carry it to completion. Other hospice staff who might also participate in conversations with patients about assisted suicide, such as spiritual care counsellors and home health aides were not surveyed.

Conclusion

Although it may seem that our results have applicability only in Oregon, other studies have demonstrated that both nurses and social workers in many settings can expect to encounter patient questions about assistance in dying whether legalized or not. Further research on assisted suicide is needed to inform the ongoing debate about this issue and to provide the necessary evidence base to guide health professionals in their care of terminally ill patients who wish to hasten death. We need to better understand how personal views may influence responses to patients and what support or education is needed in order to respond effectively.

Contributors

LL Miller – conception and design of the study, analysis and interpretation of data, drafting of the manuscript, and administrative, technical, and material support.
TA Harvath – obtaining funding, conception and design of the study, analysis and interpretation of data, critical revision of the manuscript.
ER Goy – conception and design of the study, data collection, administrative, technical and material support.
A Jackson – conception and design of the study.
MA Delorit – data collection, administrative, technical, and material support.
L Ganzini – obtaining funding, conception and design of the study, data collection, analysis and interpretation of data, drafting of the manuscript, critical revision of the manuscript, and administrative, technical, or material support.

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