

SPECIAL ARTICLE

## Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

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### ABSTRACT

#### BACKGROUND

Voluntary refusal of food and fluids has been proposed as an alternative to physician-assisted suicide for terminally ill patients who wish to hasten death. There are few reports of patients who have made this choice.

#### METHODS

We mailed a questionnaire to all nurses employed by hospice programs in Oregon and analyzed the results.

#### RESULTS

Of 429 eligible nurses, 307 (72 percent) returned the questionnaire, and 102 of the respondents (33 percent) reported that in the previous four years they had cared for a patient who deliberately hastened death by voluntary refusal of food and fluids. Nurses reported that patients chose to stop eating and drinking because they were ready to die, saw continued existence as pointless, and considered their quality of life poor. The survey showed that 85 percent of patients died within 15 days after stopping food and fluids. On a scale from 0 (a very bad death) to 9 (a very good death), the median score for the quality of these deaths, as rated by the nurses, was 8.

On the basis of the hospice nurses' reports, the patients who stopped eating and drinking were older than 55 patients who died by physician-assisted suicide (74 vs. 64 years of age,  $P < 0.001$ ), less likely to want to control the circumstances of their death ( $P < 0.001$ ), and less likely to be evaluated by a mental health professional (9 percent vs. 45 percent,  $P < 0.001$ ).

#### CONCLUSIONS

On the basis of reports by nurses, patients in hospice care who voluntarily choose to refuse food and fluids are elderly, no longer find meaning in living, and usually die a "good" death within two weeks after stopping food and fluids.

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**S**TUDIES OF TERMINALLY ILL PATIENTS show that a small proportion of them would choose physician-assisted suicide or euthanasia for reasons of hopelessness, depression, feeling unappreciated, a sense of the meaninglessness of continued existence, readiness to die, and fear of loss of independence and control.<sup>1-9</sup> Because physician-assisted death is not available to most terminally ill patients, some medical experts have suggested voluntary refusal of food and fluids as an alternative.<sup>10-13</sup> Unlike physician-assisted suicide, the choice to stop eating and drinking is legal throughout the United States, available to competent patients, and does not necessarily require the participation of a physician.<sup>11-13</sup> Some physicians assert that the moral basis for this choice is stronger than that for physician-assisted suicide or euthanasia.<sup>11,12</sup> Other physicians challenge that assertion by asking whether this behavior is different from suicide, with or without a physician's assistance, and some physicians believe that collaboration with a patient who intends to hasten death is morally impermissible.<sup>14-17</sup>

We interviewed 35 physicians in Oregon regarding their experiences with patients' requests for assisted suicide; 7 knew patients who, when confronted with barriers to obtaining a lethal prescription, chose to stop eating and drinking in order to hasten death. Because little is known about the experience of dying among patients who make this choice, we asked hospice nurses in Oregon about their perceptions of such patients. On the basis of information from these nurses, we compared hospice patients who deliberately hastened death by refusing food and fluids with hospice patients who hastened death by means of legalized physician-assisted suicide during the same period.

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## METHODS

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### QUESTIONNAIRE

We have described the methods used in this study previously.<sup>3</sup> In 2001, we mailed a questionnaire to nurses who care for Oregon residents enrolled in hospice programs. All 50 Medicare-certified home hospice programs in Oregon participated, as well as 2 hospices in neighboring states that provide services for patients in Oregon. The hospices either submitted the names of or delivered the questionnaire to a total of 429 eligible nurses.

The questionnaires were mailed with a \$10 check and were followed by a reminder postcard. For those

who did not respond, a second copy of the questionnaire was sent, followed by a reminder letter. To allow for tracking of the questionnaires, returned envelopes were coded with an identifying number. The returned questionnaires were then removed from the envelopes and recoded, rendering them anonymous. The study was approved by the institutional review board at the Portland Veterans Affairs Medical Center, which waived the requirement for obtaining written informed consent.

Nurses provided information on the one most recent patient, since November 1997, who had voluntarily chosen to refuse food and fluids. In the questionnaire, the following definition was used: "Voluntary refusal of food and fluids describes an action by a patient 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 such as loss of appetite or inability to eat or drink because of disease." Respondents were reminded of this definition at several points in the survey.

The hospice nurses were asked to rate 21 possible reasons why the patient stopped intake of food and fluids to hasten death on a scale of importance ranging from 1 (not at all important) to 5 (very important). On a 10-point scale, with end points labeled, respondents rated the patient's overall peacefulness (with 0 denoting very much at peace and 9 not at all at peace) and suffering (with 0 denoting none and 9 severe, unremitting suffering) in the two weeks before death, and the quality of the process of dying (with 0 denoting very bad and 9 very good). Respondents were asked to compare characteristics of family caregivers of patients who chose to refuse food and fluids with characteristics of the family caregivers of other hospice patients on a scale from 1 to 5 (with 1 denoting much less than other hospice patients' family caregivers and 5 much more).

Respondents were asked almost identical questions about their views and experiences with hospice patients who requested and received prescriptions for lethal medication under Oregon's Death with Dignity Act (enacted in 1997). Fifty-five nurses provided data on a patient who had died after ingesting a prescribed lethal medication. These results have been reported in full.<sup>3</sup>

### STATISTICAL ANALYSIS

Summary data are presented as frequencies and proportions for categorical variables. Many measures were not normally distributed and are there-

fore reported as medians with interquartile ranges. Groups were compared with the use of the Mann-Whitney U test. Normally distributed, continuous variables were compared with use of Student's t-test and are reported as means ( $\pm$ SD). All P values are two-sided, and the alpha level was set at 0.05.

There were two potential violations of independence of observations. First, we cannot verify that each hospice nurse reported on a unique patient. We did, however, compare demographic characteristics of patients (age, sex, size of the community in which the patient lived, marital status, disease, and type of hospice) to search for possible duplicates. Although two patients shared demographic characteristics, other distinguishing information indicated that they were not the same patient. Second, of 140 nurses who reported on a patient who had hastened death, 85 reported only a death from voluntary refusal of food and fluids, 38 reported only a death from physician-assisted suicide, and 17 reported deaths from voluntary refusal of food and fluids and from physician-assisted suicide. Because the 17 nurses who reported both types of deaths made up only 12 percent of the total number of respondents, each reported death was treated as an independent observation.

## RESULTS

Of 429 nurses, 307 (72 percent) returned the questionnaire, and of those, 126 (41 percent) reported on one patient who voluntarily chose to stop eating and drinking. Of these nurses, 16 reported that the patient subsequently resumed eating and drinking, 8 did not know the outcome of the patient's decision, and 102 reported that the patient hastened death as a consequence of stopping food and fluids. Reasons for resuming food and fluids, which were coded from written comments by 11 nurses, included family pressure or encouragement to eat (five patients), hunger or discomfort (four), amelioration of depression (one), and alleviation of other concerns (one). Three of the 102 nurses who cared for a patient who died after stopping food and fluids believed that allowing a hospice patient to hasten death deliberately in this manner was unethical. None of the nurses reported that they would actively oppose a patient's choice to hasten death by refusing food and fluids, and only one reported wanting to decline to care for such a patient.

In 31 percent of the cases reported, the patient was 80 years of age or older. The majority of pa-

tients lived in small towns or rural areas, and the most common terminal diagnosis was cancer (Table 1). The estimated life expectancy just before the patient stopped eating and drinking was less than one week for 6 percent of the patients, one week to one month for 45 percent of the patients, and more than one month for 47 percent of the patients (data were missing for two patients, or 2 percent). According to 84 nurses, the patients died a mean of

**Table 1. Hospice Nurses' Reports of Characteristics of Patients Who Died by Voluntary Refusal of Food and Fluids as Compared with Those of Patients Who Died by Physician-Assisted Suicide.\***

Characteristic	Died by Voluntary Refusal of Food and Fluids (N=102)	Died by Physician-Assisted Suicide (N=55)	P Value†‡
Age — yr	74 $\pm$ 13	64 $\pm$ 11	<0.001
Sex — no. (%)			0.13
Male	46 (45)	32 (58)	
Female	55 (54)	23 (42)	
Missing data	1 (1)		
Marital status — no. (%)			0.62
Married or living as married	49 (48)	31 (56)	
Divorced, separated, widowed, or never married	49 (48)	23 (42)	
Unknown or missing data	4 (4)	1 (2)	
Type and size of area served by hospice — no. (%)			0.21
Rural area or small town, <25,000 residents	57 (56)	23 (42)	
Medium-sized city, 25,000–250,000 residents	27 (26)	21 (38)	
Large city, >250,000 residents	18 (18)	11 (20)	
Terminal diagnosis — no. (%)‡			
Cancer	61 (60)	44 (80)	0.01
Cardiopulmonary disease	16 (16)	9 (16)	0.91
Neurologic disease	23 (23)	5 (9)	0.04
Other	7 (7)	3 (5)	0.73
Missing data	1 (1)		

\* Plus-minus values are means  $\pm$ SD.

† Frequencies were compared with the use of the chi-square test. Mean values were compared with the use of Student's t-test.

‡ Nurses could report more than one diagnosis, so the total number of terminal diagnoses can exceed the number of patients.

10±7 days after stopping food and fluids, and 71 patients (85 percent) died within 15 days. On the basis of the nurses' responses, patients who stopped eating and drinking were older, less likely to have cancer, and more likely to have a terminal neurologic

disease than were 55 patients who died by physician-assisted suicide (Table 1).

Seventy-five nurses (74 percent) reviewed the patient's decision at an interdisciplinary hospice care conference. Sixty-three patients (62 percent) were evaluated by the hospice social worker, and nine (9 percent) were evaluated by a mental health professional such as a psychiatrist, psychologist, or mental health nurse practitioner. The levels of review were similar for patients who died by physician-assisted suicide, except that 25 patients who died by ingesting prescribed lethal medication (45 percent) were evaluated by a mental health professional ( $P<0.001$ ). Twelve nurses (12 percent) reported that the patients who died after stopping food and fluids had a mental disorder such as depression, which, in their opinion, may have influenced the decision to refuse food or fluids.

According to the hospice nurses, the most important reasons for the decision to stop food and fluids were a readiness to die, the belief that continuing to live was pointless, an assessment of the quality of life as poor, a desire to die at home, and a desire to control the circumstances of death (Table 2). The least important reasons were dyspnea, mental confusion, nausea, depression or other psychiatric disorders, concern about being a financial drain, the experience of having witnessed "bad deaths," and lack of social support. The nurses rated the last two weeks of life as peaceful, with low levels of pain and suffering (Table 3). Most deaths were rated as "good" (a score of 5 to 9 on a scale of 0 to 9), though eight nurses (8 percent) rated the patient's death as "bad" (a score of 0 to 4). As compared with the 94 patients who were considered to have had good deaths, the 8 patients with bad deaths had significantly higher scores for suffering (6.1 vs. 3.2,  $P<0.001$ ) and pain (4.4 vs. 2.7,  $P=0.04$ ) and were somewhat younger ( $66\pm 14$  years vs.  $74\pm 12$  years,  $P=0.06$ ). According to the nurses, patients who chose to stop food and fluids were less likely to want to control the circumstances of their death ( $P<0.001$ ), less likely to fear loss of dignity ( $P=0.04$ ), more prepared to die ( $P=0.03$ ), and more likely to lack social support ( $P=0.04$ ) than patients who chose physician-assisted suicide (data not shown). As compared with patients who died by physician-assisted suicide, those who stopped eating and drinking were rated by nurses as suffering less and being more at peace in the last two weeks of life (Table 3).

Ninety-one hospice nurses (89 percent) spoke

**Table 2. Hospice Nurses' Perceptions of Why 102 Patients Chose to Hasten Death by Stopping Food and Fluids.**

Reason for Hastening Death*	No. of Responses†	Median Score‡	Interquartile Range
Ready to die	100	5.0	5.0–5.0
Poor quality of life or fear of poor quality of life	98	5.0	4.0–5.0
Continued existence viewed as pointless	96	5.0	4.0–5.0
Wanted to die at home	96	5.0	3.0–5.0
Desire to control circumstances of death	93	5.0	3.0–5.0
Loss of or fear of losing independence	97	4.0	3.0–5.0
Perception of self as a burden to others or fear of becoming a burden	97	4.0	3.0–5.0
Loss of or fear of losing dignity	95	4.0	3.0–5.0
Life tasks completed	91	4.0	3.0–5.0
Inability to care for self or fear of inability to do so	99	4.0	2.0–5.0
Fatigue or fear of worsening fatigue	98	4.0	2.0–5.0
Inability to engage in pleasurable activities	93	4.0	2.0–5.0
Pain or fear of worsening pain	96	3.0	2.0–4.0
Loss of or fear of losing bowel or bladder function	95	3.0	1.0–4.0
Dyspnea or fear of worsening dyspnea	94	2.0	1.0–4.0
Perception of self as financial drain on others or fear of becoming financial drain	87	2.0	1.0–4.0
Nausea or fear of worsening nausea	92	2.0	1.0–3.0
Mental confusion or fear of mental confusion	91	2.0	1.0–3.0
Depression or other psychiatric disorder	90	2.0	1.0–3.0
Experience of witnessing bad deaths	70	2.0	1.0–3.0
Lack of social support	91	1.0	1.0–3.0

\* Respondents were asked to mark only the reasons that reflected actual conversations with the patient or family.

† Some respondents marked the response "Did not know/did not discuss" or left it blank.

‡ Scores ranged from 1 to 5, with 1 denoting not important in the decision to refuse food and fluids, and 5 very important in the decision to refuse food and fluids.

with a family member about the patient's decision to stop food and fluids. Although some respondents did not speak directly with a family member, they reported on the family member's views. Eight respondents (8 percent) reported that many family members opposed the decision, whereas 87 (85 percent) reported that most or all family members accepted the decision (7 responses were missing or unknown). Overall, approximately half the hospice nurses reported that family members of patients who made this decision were more prepared for and more accepting of the ill person's death than were family members of other hospice patients (Fig. 1). Only 16 percent of nurses rated the family members as more burdened by caring for the ill person than family members of other hospice patients, and only 9 percent rated the family members as more burdened by the cost of care.

## DISCUSSION

Reports of death hastened by voluntary refusal of food and fluids are rare in the literature, and we are aware of only three clinical case reports of patients who made this choice.<sup>18-20</sup> Emanuel reported that in the entire 30-year history of St. Christopher's Hospice in England, only two patients chose to hasten death by refusing food and fluids.<sup>17</sup> In contrast, one third of hospice nurses in Oregon reported that at least one patient for whom they had cared in the previous four years (from November 1997 to the summer of 2001) had deliberately hastened death by stopping food and fluids. Even though legalized physician-assisted suicide was available to patients in hospices in Oregon during the study period, the number of reports of patients who died after stopping food and fluids was almost twice that of patients who died as a result of physician-assisted suicide. Although voluntary refusal of food and fluids may not have been common — during this period, more than 40,000 Oregon residents died in hospice care — we propose that this choice may occur often enough to be of clinical relevance to hospice care across the United States.

According to hospice nurses, patients chose to stop eating and drinking for reasons that included being ready to die, believing that continuing to live was pointless, and a sense of poor quality of life, as well as wanting to control the manner of death. Unbearable physical suffering did not appear to be an important reason for this choice. According to the nurses' reports, most deaths from voluntary refusal

**Table 3. Nurses' Assessment of the Quality of the Last Two Weeks of Life for Patients Who Died by Stopping Food and Fluids and Those Who Died by Physician-Assisted Suicide.**

Variable	Stopped Food and Fluids (N=102)	Physician-Assisted Suicide (N=55)	P Value*
Suffering†			0.007
Median	3	4	
Interquartile range	2–5	2–7	
Pain‡			0.13
Median	2	3	
Interquartile range	1–4	2–4	
Peacefulness§			0.04
Median	2	5	
Interquartile range	1–5	1–7	
Overall quality of death¶			0.95
Median	8	8	
Interquartile range	7–9	6–9	

\* Data were compared with use of the Mann–Whitney U test.

† Suffering was rated on a 10-point Likert scale, with 0 denoting no suffering at all, and 9 severe, unremitting suffering.

‡ Pain was rated on a 10-point scale, with 0 denoting no pain at all, and 9 severe, unrelenting pain.

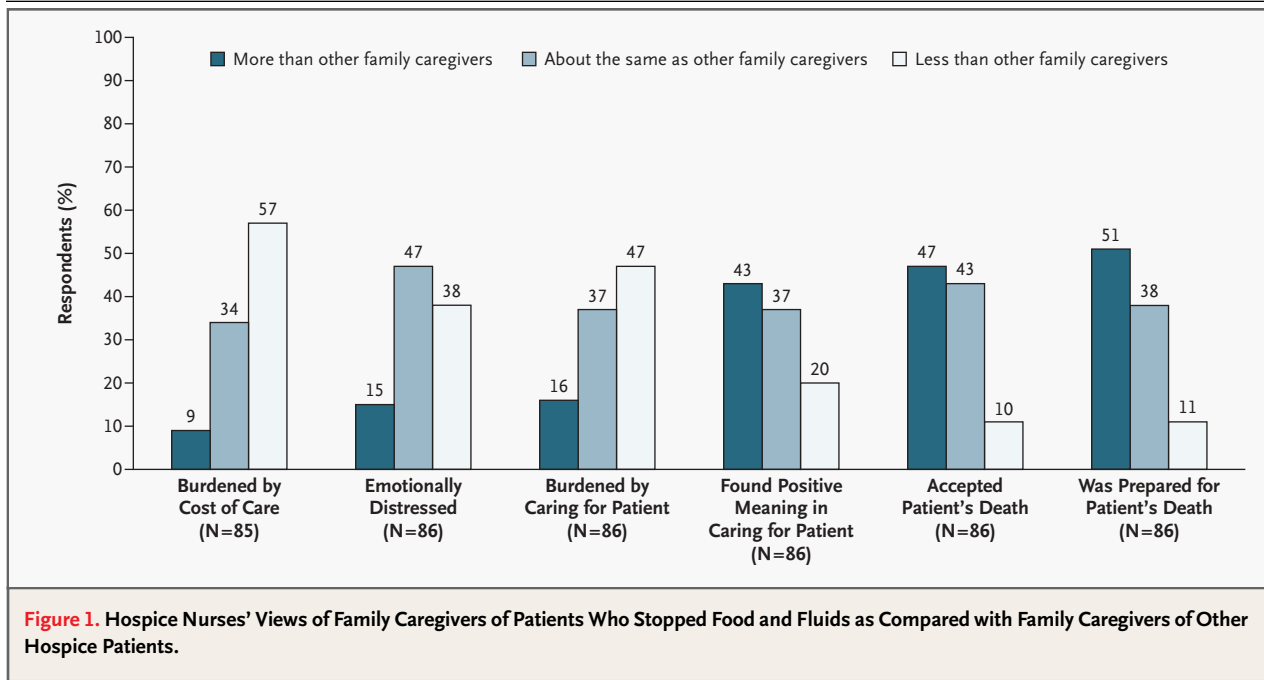
§ Peacefulness was rated on a 10-point scale, with 0 denoting very much at peace, and 9 not at all peaceful.

¶ The overall quality of death was rated on a 10-point scale, with 0 denoting a very bad death, and 9 a very good death.

of food and fluids were peaceful, with little suffering, although 8 percent of patients were thought to have had a relatively poor quality of death. Only one in eight patients whose outcome was known resumed eating and drinking, most often because of thirst or pressure from family members.

The concern has been expressed that patients who make these decisions may be affected by a depressive disorder. Both loss of appetite and a desire to die are common symptoms of depression. Depression, when severe, may influence decision making, and if it is successfully treated, patients may choose both to eat and to continue to live.<sup>21</sup> Although mental health consultation has been recommended for all persons wishing to hasten death in this way,<sup>11</sup> it was the exception rather than the rule for hospice patients in Oregon who died by voluntary refusal of food and fluids. Studies of nonpsychiatric health care practitioners show that depression is often overlooked in medical settings unless it is a factor in a rigorous assessment.<sup>22</sup>

There are similarities and differences between hospice patients in Oregon who hastened death by voluntary refusal of food and fluids and those who



died by physician-assisted suicide. The Oregon Death with Dignity Act requires a 15-day waiting period from a patient's first request for lethal medication to the day the medication is prescribed.<sup>23</sup> According to our survey of nurses, 85 percent of patients who voluntarily refused food and fluids died within 15 days. The time to death and the overall quality of dying as assessed by the nurses were similar in these two groups of patients (Table 3). The hospice nurses reported that these two groups of patients had similar reasons overall for hastening death, except that those choosing physician-assisted suicide placed more emphasis on controlling the time and manner of death. Thus, any analysis of the permissibility of voluntary refusal of food and fluids as compared with physician-assisted suicide cannot be based on patients' motives for hastening death. A preference for one means over the other may depend on the importance placed on control, access to a physician who will prescribe lethal medication, other beliefs, and family views. Anorexia, which occurs in some dying patients, may facilitate the choice to stop eating and drinking.

According to our survey, patients who voluntarily chose to refuse food and fluids were, on average, almost a decade older and were more likely to have neurologic disease than were patients who chose physician-assisted suicide. Patients with neurologic diseases such as amyotrophic lateral sclerosis may

wish to hasten death but be unable to administer the lethal medication themselves, as required by the Oregon law.<sup>1,24</sup> We did not evaluate other factors known to be important in determining attitudes about hastening death, such as religious beliefs.

There are several limitations to this study. First, the reports from hospice nurses are based on their perceptions and memories of deaths that may have occurred up to four years previously. Second, although we asked nurses to report only on patients who chose voluntarily to refuse food and fluids in order to hasten death, not because of illness-related factors, and to rate the reasons for hastening death on the basis of conversations with patients and family members, we cannot verify that these directions were clearly understood. However, subsequent qualitative interviews with 11 of the respondents confirmed that these were deliberate choices to hasten death made by apparently competent patients who were capable of drinking fluids.

Third, it is unknown whether our findings are generalizable to hospice patients outside Oregon. It is possible that the legalization of assisted suicide and an emphasis on improving end-of-life care in Oregon has heightened awareness of end-of-life choices among patients in Oregon. Health care professionals may suggest refusal of food and fluids as an option when patients request physician-assisted suicide. Fourth, 28 percent of hospice nurses in Or-

egon did not respond to our survey, and their experiences are therefore not represented.

Fifth, there may be other reasons why patients chose to stop food and fluids that were not included in our questionnaire. Finally, the analyses comparing patients who chose assisted suicide with those who stopped food and fluids were exploratory, not based on hypotheses — a fact that may increase the chance that some differences reported as statistically significant actually were not.

In summary, Oregon nurses report that some hospice patients choose to hasten death by stopping food and fluids, even though physician-assisted suicide is legal in Oregon, and that the quality of the process of dying for most of these patients is good.

Prospective studies of patients who make this choice are needed to verify hospice nurses' impressions of the reasons for the choice and to understand the physiological and psychological predictors of good deaths as compared with bad deaths in such patients, including the need for sedation to make the patient comfortable. These findings should promote further discussion among clinicians about the choice to hasten death by refusing food and fluids and about standards for evaluating and caring for patients who make this choice.

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