Attitudes of Terminally Ill Patients Toward Euthanasia and Physician-Assisted Suicide

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Background: In jurisdictions that permit euthanasia or physician-assisted suicide, patients with cancer comprise the largest group to die by these methods. We investigated the personal attitudes toward these practices of patients receiving palliative care for advanced cancer.

Methods: Seventy patients (32 men and 38 women; median survival, 44.5 days) took part in a survey using in-depth semistructured interviews. The interviews were audiotaped for transcription and content analysis of themes.

Results: Most participants (73%) believed that euthanasia or physician-assisted suicide should be legalized, citing pain and the individual's right to choose as their major reasons. Participants who were opposed to legalization cited religious and moral objections as their central concerns. Forty (58%) of the 69 participants who completed the entire interview also believed that, if legal, they might personally make a future request for a hastened death, particularly if pain or physical symptoms became intolerable. Eight of these individuals (12%) would have made such a request at the time of the interview. These 8 participants differed from all others on ratings of loss of interest or pleasure in activities, hopelessness, and the desire to die (P < .02). They also had a higher prevalence of depressive disorders (P < .05). However, they did not differ on ratings of pain severity.

Conclusions: Many patients with advanced cancer favor policies that would allow them access to both euthanasia and physician-assisted suicide if pain and physical symptoms became intolerable. For patients who would actually make requests for a physician-hastened death, however, psychological considerations may be at least as salient as physical symptoms.

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WITH THE ongoing societal debate around the issue of legalizing voluntary euthanasia or physician-assisted suicide for terminally ill patients, there has been a growing interest in identifying the concerns of those who would be most likely to make requests for a hastened death. Studies have been conducted with various groups of patients who have life-threatening illnesses. There are also reports from the Netherlands, the Australian Northern Territory, and the US state of Oregon that have described the characteristics of patients who have died by these methods in jurisdictions where they have been permitted. Finally, there are surveys of physicians in other areas who have provided euthanasia or assisted suicide, albeit illegally, to patients in their care. These studies indicate that both physical and psychosocial considerations are relevant in the assisted-suicide debate, but they are limited because they have been conducted (1) with physicians rather than with the patients themselves or (2) with patients who were not necessarily close to death, when these decisions would be most salient. In this study, we examined patients' attitudes toward these practices and to investigate the factors that are related to the personal interest in receiving a physician-hastened death.

RESULTS

RECRUITMENT

During the recruitment period, 789 patients with cancer were admitted or referred to the participating palliative care services. However, only 229 patients met the inclusion criteria for participation. The main reasons for ineligibility were that the patient was too ill to participate or died before the case was reviewed (n = 475, 85% of those excluded). The remainder were...
PARTICIPANTS AND METHODS

RECRUITMENT

The survey was conducted from 1996 to 1998. The participants were patients admitted to a regional palliative care inpatient unit or patients who received palliative care consultation services on the oncology wards of 2 Canadian tertiary care hospitals. The study protocol was approved by the ethics review committees of all the participating institutions.

At each site, the clinical palliative care teams reviewed consecutive referrals or admissions for the following inclusion criteria: (1) in the team’s opinion, the patient was medically and cognitively able to participate; (2) the patient had been informed that the malignant illness was incurable; and (3) the palliative care team was confident that broaching a discussion of euthanasia and physician-assisted suicide would not undermine their clinical role with the patient. If the patient agreed, a meeting was arranged with a research interviewer, who obtained written informed consent.

PROCEDURE

The semistructured interviews were conducted by a clinical psychologist, doctoral students in psychology, or a research associate in palliative care. All interviews were attended by both a primary interviewer and an observer, to permit the evaluation of interrater reliability. They were also audiotaped for later transcription.

The interview first addressed the subject’s general attitudes toward the acceptability and legal status of both euthanasia and physician-assisted suicide. Euthanasia was defined as an action in which “a medical doctor gives an overdose of medication to purposely end a patient’s life. This is only done with patients who have asked their doctor to help them die in this way. Usually, the patients involved are very ill with a life-threatening disease.” Physician-assisted suicide was defined as an action in which “a medical doctor provides drugs and advice, so that a patient could commit suicide. The doctor does not actually inject the drugs, but rather gives the patient the means to end his or her own life.” The subject was then asked whether each of these practices is acceptable, whether they should be legalized, and whether there are any important differences between them.

The interview then moved on to review the subject’s personal circumstances, beginning with an inquiry into physical symptoms of pain, drowsiness, weakness, nausea, and breathlessness, which are among the most prevalent problems in the final weeks of life.17-19 The protocol also addressed specific end-of-life concerns that have been relevant in previous studies of euthanasia or assisted suicide in medical populations, including the loss of control, loss of dignity, sense of being a burden to others, and hopelessness.7,8,20 Next, the interview addressed the mental health issues of anxiety, depression, and loss of interest or pleasure in activities. This section then concluded with an inquiry into the subject’s desire for death.21

Each of these 13 symptoms and concerns was assessed using interview items that began with a structured lead question, followed by a series of follow-up prompts to clarify the severity of the problem. Severity was then rated by the interviewer on a 7-point scale (none, minimal, mild, moderate, strong, severe, and extreme). The screening items for anxiety, depression, and loss of interest or pleasure were used in conjunction with the Primary Care Evaluation for Mental Disorders (PRIME-MD)22 to permit the full diagnostic assessment of discrete anxiety and depressive syndromes, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV).23-25

The last section of the interview returned to the topics of euthanasia and physician-assisted suicide, with a focus on the subject’s personal situation. Specifically, the subject was asked (1) whether he or she would have asked for euthanasia or assisted suicide, if they were legal and available, at any point in the current illness; (2) if there were any foreseeable circumstances in which he or she would make such a request in the future, and; (3) whether he or she would actually initiate a request now, in the current circumstances.

DATA ANALYSIS

The audiotaped responses were transcribed verbatim to facilitate content analysis.26,27 This is an inductive strategy that involves the process of breaking down, constantly comparing and categorizing narrative information, resulting in the identification of underlying themes. All transcripts were reviewed independently by 3 investigators (K.G.W., I.D.G., and J.F.K.), who then met as a team to reach consensus on themes. Categories of response that were provided by more than 5% of the total study group (at least 4 participants) are reported.

For the 13 clinical rating scales, the intraclass correlations between the 2 raters exceeded r=0.92 in each case. In the diagnosis of mental disorders, there was only 1 disagreement (κ=0.96), confirming that the assessments had high interrater reliability.

For the quantitative analyses, we identified subgroups of subjects who differed with respect to their personal interest in receiving a physician-hastened death. The demographic and clinical characteristics of these subgroups were compared statistically using χ² and Fisher exact tests for categorical data, and analyses of variance for continuous measures and rating scales. Significant F tests were followed up with Tukey pairwise comparisons.
services on the participating units during the study period. Limited data about age and sex were available for patients who declined participation. There were no differences in these characteristics between the patients who did and did not participate (Ps > .10).

One participant completed a partial interview before requesting a break, but was not able to complete the full protocol because of progressive illness. The partial data from this person have been included where they are available.

PARTICIPANTS

The demographic characteristics of the 70 participants (32 men and 38 women) are shown in Table 1. Their average age was 64.5 years (range, 43-88 years). In general, the study group was highly educated, with 49 participants (70%) having at least a high school education. From the date of the interview, the median survival duration of the study group was 44.5 days, with only 11 participants (16%) living as long as 6 months.

ATTITUDES TOWARD THE ACCEPTABILITY AND LEGAL STATUS OF EUTHANASIA AND ASSISTED SUICIDE

Forty-five participants (64%) considered that both euthanasia and physician-assisted suicide are acceptable practices that should be legalized, whereas 15 (21%) reported that both are unacceptable and should not be legalized. Of the remaining 10 participants (14%), 3 were uncertain, 4 reported that only euthanasia should be legalized, 1 reported that both practices are acceptable in an informal way but should not be legalized, and 2 indicated that both are unacceptable in principle but should be legalized anyway if they are going to be practiced surreptitiously.

The 51 participants who were in favor of at least limited legal access to either euthanasia or assisted suicide provided a total of 122 individual reasons to support their opinion. These reasons are summarized in Table 2. In general, they believed that people have the right to decide how they will die. Other frequent reasons referred to uncontrollable pain, diminished quality of life, and other types of suffering, both physical and mental. Some participants also expressed a concern about relieving the burden on family members, and some noted that their attitudes were influenced by their knowledge of the end-of-life experiences of others.

The 16 participants who were against legalization provided 36 individual reasons for their view, consisting mostly of opposition because of religious or spiritual beliefs, or because of secular moral values. They also raised concerns about the potential for abuse, that causing death is not an appropriate role for physicians, and that the desire to die is not always stable or rational.

PERCEIVED DIFFERENCES BETWEEN EUTHANASIA AND ASSISTED SUICIDE

Participants were also asked whether there are any important differences between euthanasia and assisted suicide. Twenty-one participants (30%) reported that they did see important distinctions between the practices; 14 (67%) found euthanasia to be more acceptable and 7 (33%) believed that physician-assisted suicide is more acceptable.

The participants who found euthanasia to be more acceptable than assisted suicide provided a total of 23 reasons for their view, including the argument that terminating life requires technical medical knowledge (n = 10,
and that physicians are best able to assess the appropriate timing, stability, and rationality of the request (n=6, 43%).

Those who considered physician-assisted suicide to be more acceptable provided a total of 11 reasons, including the concern that the direct termination of life is not an appropriate role for physicians (n=5, 71%), and that assisted suicide maximizes choice and control for the patient (n=5, 71%).

PERSONAL INTEREST IN RECEIVING EUTHANASIA OR ASSISTED SUICIDE

When asked whether they could envision future circumstances in which they would personally request euthanasia or assisted suicide, 32 participants (46%) reported that they could, 19 (28%) reported that they could not, and 10 (14%) were uncertain. Of those with a possible interest for the future, 3 participants believed that they would already have made requests at earlier points in their illness, but they no longer thought that way by the time of the interview. In addition, however, there were also 8 other patients, or 12% of the entire study group, who reported that they would request euthanasia or assisted suicide immediately, in their current circumstances.

REASONS FOR WANTING EUTHANASIA OR ASSISTED SUICIDE IN THE FUTURE

The 32 participants who indicated a possible future interest in receiving euthanasia or assisted suicide reported a total of 63 reasons for why they would make such requests. The most frequent reasons focused on the physical distress associated with uncontrollable pain (n=15, 47%) and other severe physical symptoms (n=11, 34%). Some participants also mentioned nonphysical circumstances that would motivate them to make a request, including if their global quality of life deteriorated (n=8, 25%), if they became a burden to others (n=7, 22%), if they were generally suffering (n=6, 19%), if they developed mental symptoms (n=6, 19%), if they believed that they were simply lingering while waiting to die (n=5, 16%), or if they perceived their overall situation as hopeless (n=4, 13%).

Twenty-two (69%) of these participants reported a preference for a particular method of hastened death, with the majority (n=16) preferring euthanasia over assisted suicide (n=6) (P=.03).

PATIENTS WHO WOULD REQUEST A HASTENED DEATH IN THEIR CURRENT CIRCUMSTANCES

The 8 participants who currently desired a physician-hastened death comprised 5 men and 3 women, aged 47 to 82 years. Three were married, 3 were divorced, and 2 were widowed. Three were university graduates, 3 had completed high school, and 2 had less than high school educations. Three were from the Roman Catholic faith, 3 were from Protestant backgrounds, and 2 reported no religious affiliation. The DSM-IV diagnoses within this group included 4 patients with major depression, 2 of whom had comorbid anxiety disorders, and 1 with major depression in partial remission.

When asked about the method that they would choose to end their lives, 4 participants indicated a preference for euthanasia, 2 for physician-assisted suicide, and 2 had no preference. As a group, they provided a total of 48 individual statements that clarified why they were ready to end their lives. In general, they recognized that their illness was terminal (n=4, 50%; eg, “For two months I have known that it was over for me.” “I have a terminal disease. I’m not going to get better.””), and they believed that they had achieved some degree of acceptance that they were going to die (n=4, 50%; eg, “I’m in a position now in my life where I want to go.” “I’d like to make my peace and go.”). They spoke of suffering (n=4, 50%; eg, “The family won’t suffer and I won’t suffer.” “If suffering is inevitable, they [the patient] should have a say.”) and of a diminished quality of life (n=4, 50%; eg, “If a patient feels he can no longer function and is no more a human being,” “God put us here to enjoy life. He didn’t cause my illness but, I mean, I’m deteriorating and that’s that.”). They believed that they had the right to exercise choice and control over the manner of their deaths (n=6, 75%; eg, “I think I should have control over dying in dignity. “Nobody should be forced to stay alive by other people.”) and that euthanasia or assisted suicide would provide an easier means of dying than they were actually experiencing (n=5, 63%; eg, “You only have to press a button to finish it and sleep peacefully.” “Just to expire in my sleep would be the perfect way for me.”). Pain was cited as a contributing reason by 1 person, although a fear of pain was discussed by another, and adverse reactions to narcotic analgesics were reported by a third.

Four of the 8 participants died within 2 weeks of the interview, and 3 others died over the next 1 to 4 months. The last patient rallied medically during the admission, and lived for another 20 months.

CLINICAL CORRELATES

Statistical comparisons were conducted between 3 groups: (1) those who would never consider euthanasia or assisted suicide (n=19); (2) those who would consider it in the future, but who had no current interest (n=32); and (3) those who would make requests in their current circumstances (n=8) (Table 3).

The 3 groups did not differ on any demographic characteristic (Ps>.10). Similarly, they did not differ with respect to the level of pain that they experienced, or in the subjective sense of depressed mood (Ps>.10). However, there were a number of differences between groups in the severity of other symptoms and concerns, including drowsiness (P=.02), weakness (P=.04), loss of control (P=.04), loss of interest or pleasure in activities (P=.007), hopelessness (P<.001), and desire for death (P<.001).

In post hoc comparisons, participants with no interest in receiving a hastened death and those with only a hypothetical future interest did not differ on any measure (Ps>.05). Rather, the 8 participants with a current interest accounted for all of the significant findings. They reported greater loss of interest or pleasure in activities,
Despite widespread interest in the issues of euthanasia and physician-assisted suicide for people who are terminally ill, this study is the first to have directly examined the attitudes of patients who are nearing death from advanced cancer. Although it would have been preferable to have achieved a higher response rate than 47% of patients approached, the difficulties of recruitment in the palliative care setting are well known. It is also important to note that most of the participants in the present study were gravely ill, the protocol was quite rigorous, and the topic is controversial. We suspect that these are the major reasons for the observed rate of refusal. Nevertheless, it must be acknowledged that the patients who chose not to take part in the study may have differed in important ways from those who did.

With this proviso, our findings agree with those of others who have reported that the majority of patients with life-threatening illnesses support the general principle of legalizing euthanasia or physician-assisted suicide. The qualitative aspects of the protocol also shed light on the reasons that underlie patient preferences. It is apparent from these reasons that people with different opinions about legalization are not simply arguing for different sides of the same issue; rather, their positions are grounded in different issues altogether. People who are against legalization are motivated primarily by religious or secular moral concerns, which place the sanctity of human life above other considerations. Those who are in favor of legalization are more concerned about the relief of uncontrollable pain and suffering, as well as with the rights of the individual to exercise choice and control. These are fundamental differences in the premises on which the 2 positions are based, which suggests that there is little common ground between them on which to reach a compromise solution.

In the United States, the movement toward legalization has focused mostly on the specific issue of assisted suicide, as reflected in the Oregon Death With Dignity legislation. Nevertheless, many right-to-die activists have acknowledged that their long-term goal includes access to euthanasia as well. The pro-legalization participants in the present study clearly saw euthanasia as being at least as acceptable as assisted suicide. Among those who would personally consider requesting a hastened death, euthanasia would actually have been the more common choice. This finding parallels the experience of the Netherlands, where euthanasia takes place much more frequently than assisted suicide. The arguments in favor of assisted suicide include concerns about patient autonomy and control, the moral limits of medical intervention, the potential for error or abuse, and the possibility of greater legal safeguards for physicians. Patient preferences have seldom been cited as a relevant factor in this debate. Indeed it can be argued that patient preferences are not relevant if they point to a position that is immoral and unethical. At the empirical level, however, it is apparent that many terminally ill patients see a role for euthanasia. This is largely because they view the termination of life as requiring an advanced technical knowledge of medicine.

Almost half of the participants could imagine future circumstances in which they would personally ask for assistance in hastening their own deaths. The most common circumstances involved scenarios of uncontrolled pain and physical symptoms. For these individuals, there might be some comfort in knowing that euthanasia or assisted suicide were available, in the event that their worst fears about pain and symptoms indeed came true. These desperate situations remain hypothetical future events for this group, however, and in the meanwhile they are doing their best to carry on. Apart from their accepting attitude toward euthanasia and assisted suicide, their clinical profiles appear to be quite similar to those of patients who would never request a hastened death.

On the other hand, the 8 participants who would have made requests for euthanasia or assisted suicide in their current circumstances appear to be quite different from the others who took part in this study, and they illustrate some of the key issues that have emerged in the legalization debate.

First, it is not always a straightforward task to specify when a life-threatening illness has entered a terminal...
phase.³ Three other participants reported that they would have requested a hastened death at earlier points in their illness, but they would no longer have done so by the time of the interview.

Third, the current desire for a physician-hastened death was associated with a high prevalence of depressive disorders. This is significant in the present context because depression is a potentially treatable problem, which in severe cases may bias health decisions in a negative way.³⁷ The clinical diagnoses of depression did not always arise from reports of a greater subjective sense of depressed mood, however, and none of the participants explicitly mentioned depression as the reason for wanting to die. Rather, the diagnoses were sometimes based in the report of a pervasive loss of interest or pleasure in activities, which is also a core criterion symptom of depressive disorders.³⁵ When coupled with a sense of hopelessness and loss of control, which were also elevated among these individuals, euthanasia and physician-assisted suicide may be seen as offering the relief of an easier death.

Fourth, of the physical symptoms that we examined, weakness and drowsiness showed the strongest association with the desire for a hastened death. It is not clear whether these symptoms directly cause the desire to die, or whether they arise because of other factors, such as a higher use of sedating medications in the treatment of this distressed group, more advanced physical disease and nearness to death, or whether they emerge as part of the symptom complex of depression in the medically ill. It is noteworthy, however, that pain, although common at low levels in the majority of participants, did not differ significantly between the groups. Among the general public, support for legalization is highest in scenarios that involve terminally ill patients who have uncontrollable pain.³ Public support is lower in scenarios that involve patients who have adequate pain control, but who want to die because of physical debility or a perceived loss of purpose and meaning.³ In reality, patients in the latter circumstances may be more characteristic of those who would actually make requests for hastened death. Therefore, if legalization is to be reviewed on a more widespread basis, the public debate should be broadened to include a discussion of the acceptability of these factors as reasons to provide euthanasia or assisted suicide.

Finally, it must also be noted that all of the participants in this Canadian study had access to state-funded palliative care services, at no personal financial cost. Unfortunately, this is not the case for every person who is facing death. The lack of accessible palliative care is a compelling argument for prudence in the review of prohibitions against euthanasia and physician-assisted suicide.³⁸,³⁹ We also have much to learn about patients’ perceptions of quality end-of-life care, and how to provide it.⁴⁰ Nevertheless, even with good care, it is evident that there will still be patients who would prefer to end their lives through direct physician intervention.⁴¹ Our results indicate that it is not necessarily extreme physical distress that motivates this desire. Rather, the psychological and existential dimensions of suffering—which are, perhaps, no less central in determining quality of life—also emerge as important reasons behind patient requests for physician-hastened death.

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