

Motivations for Physician-assisted Suicide

Patient and Family Voices

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OBJECTIVE: To obtain detailed narrative accounts of patients' motivations for pursuing physician-assisted suicide (PAS).

DESIGN: Longitudinal case studies.

PARTICIPANTS: Sixty individuals discussed 35 cases. Participants were recruited through advocacy organizations that counsel individuals interested in PAS, as well as hospices and grief counselors.

SETTING: Participants' homes.

MEASUREMENTS AND RESULTS: We conducted a content analysis of 159 semistructured interviews with patients and their family members, and family members of deceased patients, to characterize the issues associated with pursuit of PAS. Most patients deliberated about PAS over considerable lengths of time with repeated assessments of the benefits and burdens of their current experience. Most patients were motivated to engage in PAS due to illness-related experiences (e.g., fatigue, functional losses), a loss of their sense of self, and fears about the future. None of the patients were acutely depressed when planning PAS.

CONCLUSIONS: Patients in this study engaged in PAS after a deliberative and thoughtful process. These motivating issues point to the importance of a broad approach in responding to a patient's request for PAS. The factors that motivate PAS can serve as an outline of issues to explore with patients about the far-reaching effects of illness, including the quality of the dying experience. The factors also identify challenges for quality palliative care: assessing patients holistically, conducting repeated assessments of patients' concerns over time, and tailoring care accordingly.

KEY WORDS: physician-assisted suicide; euthanasia; decision making; end-of-life issues; qualitative research.

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The motivation to pursue physician-assisted suicide (PAS) has been an important issue in the debates regarding the legality and appropriate response to requests for PAS. Understanding the motivation is critically important to physicians because many of them have been asked for assistance in PAS.¹⁻³ Previously described explanations include inadequate treatment for pain or other symptoms (i.e., inadequate pallia-

tive care),¹⁻⁷ psychiatric problems (e.g., depression, hopelessness),⁷⁻¹³ and concerns about losses (e.g., function, control, sense of community, sense of self).^{5,6,14-17}

However, these explanations are principally based on three sources of evidence: physicians' impressions, patients' reports of hypothetical circumstances under which they would consider PAS, and survey data from Oregon. There is limited direct reporting from patients and family members about what drives patients to pursue PAS.

To address the current gaps in our understanding, we conducted a longitudinal qualitative study with patients who seriously pursued PAS, and their family members. This study expands the medical and ethics literature on end-of-life care by providing a detailed descriptive account of the pursuit of PAS from the perspective of patients and their family members.

METHODS

Participants

A detailed account of the recruitment and methods is described elsewhere.¹⁸ Briefly, we recruited patients who were seriously pursuing PAS and their family members (ongoing cases), as well as family members of persons who had seriously pursued and/or died of PAS (historical cases). We recruited participants through advocacy organizations that counsel people interested in a hastened death (see Table 1 for definitions), hospices, and grief counselors. The referral sources sent information to their clients and/or verbally informed them about the study. All participants voluntarily contacted us. Patients were screened for decisional incapacity, which, if found, would have precipitated a series of actions to protect the patient. Specifically, we looked for evidence that would suggest that pursuit of a hastened death was motivated by a psychiatric disorder (e.g., severe depression, delusions).

To protect respondents' confidentiality, we destroyed all records with personal identifiers and removed identifying information from transcripts. All study procedures were reviewed and approved by the university's Institutional Review Board.

Data Collection

We conducted qualitative, semistructured interviews with patients and family members. Five investigators conducted interviews; for each family, the same investigator interviewed all members. In total, we conducted 159 interviews with 60 participants concerning 35 patients between April 1997 and March 2001. Patients and family members for ongoing cases were interviewed at enrollment and at approximately 3-month

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Table 1. Definitions

Physician-assisted suicide (PAS). The physician prescribes medications to the patient knowing that the patient plans to self-administer them to cause death and end suffering.
Voluntary euthanasia. At the request of a patient, the physician or another person causes the patient's death by giving a medication. Herein, the term also refers to family members giving medications to patients (who have previously requested PAS) to hasten their death, and thus end suffering.
Hastened death. A lay term for physician-assisted suicide. This term was used by many of our informants who thought it represented a neutral term that differentiates aid-in-dying for people with terminal illness from suicide by those with mental illness. In the narrative of this paper, we use the term hastened death, rather than PAS and voluntary euthanasia, to reflect the views of our informants.

intervals until the patient's death. Family members of deceased patients (ongoing and historical cases) were interviewed on average 2.4 times.

The interview guide included open-ended questions about the history of the illness, the reasons for and other factors influencing the pursuit of a hastened death, and the manner of death. Additional details of the interview are presented elsewhere.¹⁸ To enhance trustworthiness of the data, all interviews were audiotaped and transcribed. In addition, all members of the multidisciplinary research team read the transcripts in their entirety, discussed them at weekly meetings, and generated follow-up questions for the interviewer, when appropriate.

Analyses

These results are based on multiple readings of the entire transcripts. Using content analysis methods,¹⁹ the team developed primary codes, such as *reasons for a hastened death* and *catalytic factors*, to classify sections of the transcripts. The interviewer and another investigator independently coded all transcripts and met to resolve coding disagreements. Significant coding discrepancies were discussed and resolved at weekly team meetings.

For each case, two investigators (R.A.P. and C.H.) independently reread the relevant sections of the transcripts, and identified the apparent motivations for the patients' pursuit of a hastened death. Respondents frequently volunteered motivations in the context of their stories, and when they did not, the interviewers specifically probed for explanations of their interest in hastening their death. These two investigators developed detailed memos for each patient, rating the relative importance of each identified issue based on the context of the patient's overall story and the emphasis given to the issues in the narrative (see Table 3 footnote for a description of the rating process). In the cases with both patient and family member interviews ($n=12$) and the 5 historical cases with multiple family members, we found that respondents reported similar issues. Thus, our judgments of importance were informed by these multiple reports.

The two internists (R.A.P. and A.L.B.) independently reviewed the narratives of the 25 patients who hastened their death to estimate each patient's life expectancy at the time of death. They concurred in their assessments for 23 of the 25 cases, and after discussion resolved the two disagreements. The psychiatrist (A.J.B.) reviewed the transcripts for evidence of major depression and formulated a psychiatric profile for each case.²⁰ The interview guide did not include a depression

questionnaire due to concerns that this would decrease subject participation. A more detailed description of this review is reported elsewhere.²⁰

RESULTS

Participant Characteristics

We studied 35 cases of patients who pursued a hastened death (Table 2). These participants are described in detail elsewhere.^{18,20} In brief, all patients were white, over half were married or living with a partner, and nearly half were widowed or divorced. Approximately one third of the participants were Protestant, 17% reported no religious preference, and 16% reported being atheist. Two thirds of the patients drew strength from their spiritual beliefs; the remainder did not consider spirituality in their deliberations about hastening their death. Nineteen patients had received disease-modifying treatment or attempts at curative treatment earlier in the course of their illnesses.

While all patients seriously pursued a hastened death, 17 patients self-administered medications, 8 patients were too ill so family members administered the medications, and 1 patient used a shotgun after he was unable to obtain medications. Eight patients died of their underlying illness and 1 patient was alive at the study's conclusion.

Motivating Issues

Our analysis identified 7 common influential issues within 3 categories: illness-related experiences, changes in the person's sense of self, and fears about the future (Table 3). The case in Table 4 illustrates how these issues evolve and interact over time.

Illness-related Experiences.

Feeling weak, tired, and uncomfortable. In 24 cases, physical changes and symptoms were judged by the investigators as influential in the individual's pursuit of hastened death. Many different symptoms became unacceptable (e.g., shortness of breath, fatigue, diarrhea). The effects of medications and treatments also were an issue. One respondent reported that his partner, who had severe thrush due to AIDS, lost 3 days each week to Amphotericin B, which was "horrible for him." Another patient described her response to steroids:

The side effects of the treatment are unacceptable . . . the Prednisone destroys you. For example, it destroys your muscles. My thighs are so weak I can't get up from the floor, and I don't have the energy to exercise. The whole thing is a vicious circle. . . . My face . . . looks like a melon. . . . I look like a frog in heat. (Case 23)

The participants' symptoms often shared several qualities: they caused suffering, were expected to get worse, interfered with the patient's functioning and quality of life, and contributed to undermining the person's identity and sense of self. As one woman with ovarian cancer stated, ". . . the terrible weakness and the nausea and just not feeling like you can do anything. . . . And it's kind of like goals that I actually have or things that I want to accomplish are slowly being taken away . . . it's kind of like the realm of the possible . . . is shrinking" (Case 2).

Pain and/or unacceptable side effects of pain medications. Pain, judged to be influential in 14 cases, functioned as a motivation in several ways: it could be unbearable, pre-occupying, or consuming. One patient reported,

Table 2. Patient Characteristics

Characteristic	Historical Cases* (N=23)	Ongoing Cases* (N=12)	Total Patients (N=35)
Mean age, y (range)	66 (33–99)	72 (60–89)	68 (33–99)
Gender (n, female)	11	6	17
Underlying illness, n			
Cancer	14	8	22
AIDS	4	1	5
Neurological diseases	4	1	5
Other†	1	2	3
Life expectancy at time of hastened death‡			
< 1 week	6	4	10
1–4 weeks	7	0	7
1–6 months	4	1	5
> 6 months	1	2	3
Past history of probable or possible major depression§	5	6	11
Possible major depression without decisional incapacity during the planning phase§	3	0	3

*The data for 23 historical cases were obtained from 52 interviews with 28 family members of patients who had seriously pursued and/or died of patient-assisted suicide (PAS). The data for ongoing cases were obtained by interviewing 12 patients actively pursuing PAS and 20 of their family members prior to the patient's death (35 and 41 interviews, respectively). After these patients died, we conducted 31 additional interviews with their family members.

†Other includes the following diagnoses: autoimmune disease, bronchiolitis obliterans, and a debilitating unexplained pain syndrome.

‡Estimated life expectancy death based on independent assessments by two internists (R.A.P. and A.L.B.).

§Basing on available data from multiple participants, the psychiatrist (A.J.B.) formulated a clinical impression of possible or probable major depression and decisional incapacity for each case. Probable depression was inferred when the narrative indicated that the patient met Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) symptom and duration criteria, and the narrative provided additional support including reported effects on functioning. Possible depression was inferred when symptom criteria were met, but the symptom duration was uncertain. One of the 11 past histories of major depression was thought to be probable and it occurred in a retrospective case; the rest were classified as possible. All cases of major depression during the planning stage were thought to be possible.

The pain could happen immediately or it could happen an hour or two later. And then I have to see about seeing [my provider] again.

It is a treadmill that I'm on; I can't get off of it, and I've had it. And I can't live like this anymore. (Case 30)

In addition, a few patients worried about the unacceptable, mind-altering effects of pain medications. A woman with cancer explained,

Well, the pain that I had before with the rheumatoid arthritis I knew that I could handle— But this pain that I have, I'm not sure—I can't get rid of it with the pain medicine always. . . . To give me enough to keep that pain under control, they'd have to put me out, and I don't want my son to have to take care of a bed patient. (Case 6)

Loss of function. For two thirds of our participants, loss of function, ranging from losing the ability to read the newspaper or socialize with friends to the inability to eat and go to the bathroom, motivated patients' interest in a hastened death. These losses were inextricably intertwined with these patients' physical changes.

Patients and their families viewed functional losses as markers of the patient's transition from life to death. A number of patients viewed the onset of incontinence or the inability to get to the bathroom as a sentinel event in their decision-making process. A daughter described her mother's experience stating,

She was totally bedridden. She was messing her sheets and stuff like this, and Mother just—I mean, she's just—she was a very fastidious person. And she just—she—well, basically, she thought the quality of her life was appalling. She couldn't do anything. All she could do was lie in bed. (Case 26)

Many patients accommodated over time to functional losses. Eventually, however, the losses became too great. As one family member explained,

[My husband had] let go of so many things along the way and kind of made do. [He'd say], "Okay, well, now I can't walk anymore. Well, I sure like being on this couch." Then he lost something else But when he could no longer take in fluids, I think that really kind

Table 3. Motivating Issues for Pursuing a Hastened Death*

Motivating Issues	Historical Cases (n=23)	Ongoing Cases (n=12)	Total Patients (N=35)
Illness-related experiences			
Feeling weak, tired, and uncomfortable	18	6	24
Pain and/or unacceptable side effects of pain medication	10	4	14
Loss of function	18	5	23
Sense of self			
Loss of sense of self	17	5	22
Desire for control	15	6	21
Fears about the future			
Fears about future quality of life and dying	12	9	21
Negative past experiences with dying	11	6	17

*Motivating issues were rated independently by two investigators (R.A.P. and C.H.) as to their role in influencing the pursuit of a hastened death. Four response categories were recorded: not mentioned, present but not judged to be influential, influential, and very influential. The latter two ratings are combined and reported in the table.

Table 4. Illustrative Case Demonstrating Dynamic and Interactive Motivations for Pursuing a Hastened Death*

When Anna was 62 years old she was diagnosed with metastatic ovarian cancer. Throughout her life, Anna was organized, energetic, and athletic. She was actively involved in community activities; she was a professional, and an involved grandparent. Her philosophy about her illness was, "I'm trying not to change my life and let cancer steal any more of it than it has to." She also had long-standing beliefs about having control over her life and death, saying, "... it should be up to me to decide ... when I've had enough suffering. ... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore."

Anna tried numerous different anticancer treatments. Over four years she underwent multiple surgeries and rounds of chemotherapy and radiation. Many of her treatments were quite uncomfortable. She reported, "[I was] deathly ill after every [chemo] treatment, just not even able to read or barely even watch television. I would wake up in the morning with dry heaves and being incontinent and rolling out of bed so I wouldn't get the bed messed up. It was really wretched." She talked about weighing the burdens of treatment against the burdens of disease, and decided to obtain the medication needed for hastening death. Anna talked to her family and after receiving their permission, obtained medications so she could hasten her death if necessary. She reported, "I felt I had more energy to fight the cancer and just to live in the present time. It just took a big weight off my shoulders somehow, knowing at least that that was one thing that maybe I didn't have to worry about." It was another three years before Anna used the medication to hasten her death.

Anna also experienced painful complications, including bowel obstruction and spinal cord compression. Despite enduring significant amounts of pain, Anna never cited pain as the motivation for a hastened death. Her primary concern was dying in a hospital, "away from my home with familiar people and familiar surroundings and some privacy and some control."

After exhausting her anticancer treatment options, Anna became very weak, sleeping much of the day, and unable to perform many of her routine functions. She started bleeding uncontrollably from her bowel as a late side effect of abdominal radiation and was told that the only treatment was repeat transfusions. Her physical frailty, prospect of a future in the hospital receiving continuous transfusions, and the loss of control all felt like her worst fears were coming true. After returning home from a transfusion only to immediately begin bleeding again, she told her husband, "Honey, this is it. I can't do this anymore." Over the next 36 hours, Anna gathered her family together to say good-bye. She ingested the medication to hasten her death with 12 loved ones in attendance and died within 2 hours.

*Adapted with permission from New York State Task Force on Life and the Law.

of pissed him off, because he had just been saying, "God, I'm so glad I have this Gatorade. This is the best. This is keeping me alive." ... I think he couldn't find any more pleasure.
(Case 21)

One woman's account exemplifies how these losses affected her mother's sense of self and attitudes about dying: "The things that were meaningful to [my mother] in her life were her art, her ability to do her art and her friends, and spending time with her friends and cooking and eating. And she was ... very convinced that when she couldn't do any of those things anymore, her life would be meaningless, and she wouldn't want to live anymore" (Case 7).

Sense of Self.

Loss of sense of self. Almost two thirds of participants pursued a hastened death because they were concerned about how dying was eroding their sense of self. Patients expressed concern about losing their personality, "source of identity," or "essence." Without the ability to maintain aspects of their life that defined them as individuals, life lost its meaning and personal dignity was jeopardized. "I'm not comfortable, and I can't do anything, so as far as I'm concerned in quality of life I'm not living; I'm existing as a dependent non-person. I've lost, in effect, my essence" (Case 23). One family member explained that her mother realized that "she was going to lose significant ability to be the person she was" (Case 1). The partner of a patient with AIDS stated:

He didn't want to kill himself; he didn't want to die. It was about finding any method to be vital and the list was narrowed down to the most—the simplest things, and when they were gone, he didn't have a reason ... So it wasn't just the diarrhea or the lack of driving; it was just losing, like, his definition—what his sense of vitality was. And when that was gone, then he was ready.
(Case 19)

Several patients mentioned that they did not want to be remembered as ill and frail. One patient reported, "... not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don't want that image

of me for me, and I don't want that image to be kind of a last image that my daughters and loved ones have of me. And that's just a dignity issue" (Case 4).

For some, being cared for and losing independence was an assault on their sense of self. For these individuals, sense of self was closely linked to their desire for control. One daughter described her mother's reaction to her favorite hospice nurse's care for a fecal impaction:

The nurse was over there, basically, manually helping her along. ... And she just said, "This is not worth it." ... And a lot [had] to do with her as a person where she just was so independent. The whole idea of nursing to her was just abhorrent. (Case 34)

Desire for control. In 21 cases, the patient's desire for a hastened death was linked to a long-standing sense of independence and desire to maintain control over future events. One family member described her mother as "an extraordinarily independent person, absolutely needing to be in control of her life all the time and already felt—how shall I put it—she had problems with feeling not in control" (Case 7). Another woman with lung cancer described her attitude toward hastened death as,

I will do things my way and the hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing ... what will be, will be; but what will be, will be done my way. I will always be in control. (Case 3)

Fears About the Future.

Fears about future quality of life and dying. While many motivational issues were based on current experiences, another common motivation was fear about the future. We judged this as influential in 21 cases. Such concerns were often affected by past experiences. For example, one patient's fears about pain and pain management were rooted in her past experience with pain due to a lifetime of severe arthritis. She told us, "I don't want to get to the place where I'm rum-dummy with morphine, because I almost reached that spot ... and I couldn't even make out a check" (Case 6).

Fears were usually associated with other motivating issues, such as loss of control, physical and functional decline, becoming a burden on family (noted to be influential in 3 cases), and loss of one's sense of self. However, what separated the fears from the other issues was their anticipatory nature. As one family member stated, "He said that he doesn't want to just turn into this vegetable kind of person where you're not aware of what's going on, and that everybody around you is affected; everybody's having to take care of you, feed you, clean you, give your medication" (Case 4). Often these fears pertained to lingering or prolonging death through the use of medical technologies. One family reported, "Living there and existing for three, four, five, six months. Living with tubes coming out of every orifice . . . that's what frightened her" (Case 14).

Negative past experiences with dying. In half the cases, negative personal experiences with the death of a loved one added to patients' interest in hastened death. One patient reported the following reaction to his mother's dying experience:

[T]here's no question about wanting to make provisions for a hastened death should conditions become so unbearable. I want to spare my family as much of that grief as I can . . . [My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her. . . . And just watched her waste away. And what a terrible way to go. (Case 24)

DISCUSSION

Our data suggest that the pursuit of a hastened death was motivated by multiple, interactive factors in the context of progressive, serious illness. These patients considered a hastened death over prolonged periods of time and repeatedly assessed the benefits and burdens of living versus dying. None of the participants cited responding to bad news, such as the diagnosis of cancer, or a depressed mood as motivations for interest in hastened death. Lack of access to health care and lack of palliative care also were not mentioned as issues of concern. These findings are comparable to those reported in Oregon.^{6,16}

This report emphasizes the importance of 3 general sets of issues: the effects of illness (e.g., physical changes, symptoms, functional losses), the patient's sense of self (e.g., loss of sense of self, desire for control), and fears about the future. The cases also illustrate that pain is often not the most salient motivating factor. Thus, this report corroborates and expands known findings.^{2,5,6,15,16,21-23} This research adds to the literature by providing rich descriptions from patients and family members about interactions between these issues and the meaning that patients ascribe to current and/or anticipated illness experiences.

Many participants identified the effects of the illness on two very personal attributes that often give life meaning: a person's desire for control and sense of self. When the effects of the illness and/or treatment attack these deeply personal values, a hastened death is viewed as a means to stop this process and minimize the damage. These feelings have been reported among patients with AIDS.^{17,24}

The influence of some of the issues in this study differed from previous reports. For example, while the effect of pain on patients' decisions to hasten death has been widely discussed, our participants mentioned pain much less frequently than

they mentioned the loss of meaningful activities and physical functioning.^{4,25} Similarly, burden on family was influential in only 3 cases, although this may reflect that family members were the reporters for two thirds of our cases.^{2,15,21}

Depression and hopelessness have been suggested as causal factors in the pursuit of a hastened death⁷⁻¹³ because they often precede suicide attempts among patients who are not terminally ill,²⁶ and studies of depressed patients with HIV and cancer have documented interest in PAS.^{9,11,27-30} Depression and hopelessness were not significant issues for our sample, although fears about future quality of life and dying may reflect hopelessness when it is understood to mean negative expectancies about the future and one's ability to change it. In the 3 patients with possible depression, their interest in a hastened death preceded any alteration in mood, and thus, in our judgment, their possible depression did not impinge on decisional capacity.

Importantly, other forms of psychological suffering motivated the patients in this study toward a hastened death. They experienced severe losses (e.g., bodily integrity, functioning, control) as existential suffering that undermined their personal sense of who they were.³¹ This loss of sense of self (often described in terms of a loss of vitality, essence, personal definition) highlights the threats of dying to the social construction of life's meaning.³² This may be especially salient among individuals living in a secular culture.

Two minor differences between the ongoing and historical cases are noteworthy. Patients seeking a hastened death more frequently expressed their fears and expressed their ongoing deliberations about decisions. Family members presented more of a complete story about the patients' illness. These differences are not surprising based on the different vantage points of the participants. Overall, however, similar issues were reported, lending support to the validity of the motivating issues we identified.

The results should be viewed in the context of the study's limitations. Our participants were a highly self-selected group: they were recruited from advocacy organizations that counsel patients interested in PAS and agreed to participate. Thus, these patients may not be representative of others who pursue a hastened death. In addition, depression may be underrepresented because 1) depressed patients may volunteer less for research, 2) our indirect, informal assessment may have been insufficient, and 3) depression may have served as an exclusion by the advocacy organizations for providing support.

Several important implications for clinicians emerge from these cases. First, the dynamic and interactive nature of the motivations challenges health care providers to understand the holistic illness and dying experience of patients. These data confirm the recommendation, espoused in high-quality palliative care, that providers repeatedly assess the patient's concerns about losses and dying in order to understand and tailor end-of-life care to the patient's changing personal experience.⁴ Second, the motivating issues can serve as an outline of topics for talking to patients about the far-reaching effects of illness, including the quality of the dying experience. Clinicians should explore a patient's fears, and how the patient sees herself in light of current and future physical decline and functional losses.³³ A patient's request for assistance with a hastened death should generate a thorough evaluation of the patient's motives and attempts at ameliorating the patient's suffering.

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