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The case for physician assisted suicide: how can it possibly be proven?

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In her paper, *The case for physician assisted suicide: not (yet) proven*, Bonnie Steinbock argues that the experience with Oregon's Death with Dignity Act fails to demonstrate that the benefits of legalising physician assisted suicide outweigh its risks. Given that her verdict is based on a small number of highly controversial cases that will most likely occur under any regime of legally implemented safeguards, she renders it virtually impossible to prove the case for physician assisted suicide. In this brief paper, we suggest some ways that may enable us to weigh the risks and benefits of legalisation more fairly and, hopefully, allow us to close the case for physician assisted suicide.

On November 8, 1994, the US state of Oregon passed the Death With Dignity Act permitting physician assisted suicide. Because of a legal injunction, implementation of the act was delayed by almost three years. After multiple legal proceedings, including a petition that was denied by the United States Supreme Court, the Ninth Circuit Court of Appeals finally lifted the injunction on October 27, 1997. Ever since, Oregon has been the only state in the US where physician assisted suicide (PAS) is a legal medical option.

The Death With Dignity Act (DWDA) allows mentally competent, terminally ill patients who are over 18 years of age and residents of the state of Oregon to obtain a prescription for a lethal dosage of medication to end their own life in case their suffering becomes unbearable. Patients eligible for the act must make one written and two oral requests over a period of 15 days. The prescribing physician and a consulting physician have to confirm the diagnosis and the prognosis. If either doctor believes the patient's mental competence is impaired, he must be referred for a psychiatric or psychological evaluation. The prescribing physician is required to inform the patient of potential alternatives to PAS, such as comfort care, hospice care, and pain control.[1]

Between 1997 and 2004, 208 individuals died under the provisions of the DWDA. In 1998, 16 Oregonians used PAS, followed by 27 in 1999, 27 in 2000, 21 in 2001, 38 in 2002, 42 in 2003, and 37 in 2004. Thus, PAS accounts for only one in 1,000 deaths among Oregonians. Interestingly, about 36 per cent of patients who obtained a lethal dose of barbiturates from a doctor never used it, suggesting that all these patients sought was control over the manner and timing of their deaths. As Timothy E Quill recently put it: ''Perhaps the knowledge that they could end their life if they so desired makes them feel less trapped—and therefore freer to keep going''.[2]

The most frequently reported reasons for choosing PAS under the DWDA are ''loss of autonomy'' (87%), ''loss of dignity'' (80%), and ''loss of the ability to enjoy the activities that make life worth living'' (84%). Concerns about being a ''burden on family and friends'' (36%), ''fear of excruciating pain'' (22%), and financial problems (3%) are surprisingly low. Of the 208 patients, 196 died at home; only one died in an acute care hospital.

Opponents of the act predicted that the patients most likely to avail themselves of PAS would be the poor, the ill educated, and the uninsured who are without access to adequate hospice care.[3] According to the Oregon Department of Human Services, however, which monitors compliance with the DWDA, the overwhelming majority of patients seeking physician assisted suicide are financially well off, highly educated, and have health insurance. On average, 86 per cent of patients using the act are enrolled in hospice care. As a matter of fact, it seems that the legal option of PAS may actually have contributed to the improvement of end of life and hospice care in Oregon. As the Oregon Department of Human Services points out:

> While it may be common for patients with a terminal illness to consider physician assisted suicide, a request for a prescription can be an opportunity for a medical provider to explore with patients their fears and wishes around end of life care, and to make patients aware of other options. Often once the provider has addressed patients' concerns, they may choose not to pursue physician assisted suicide. The availability of assisted suicide as an option in Oregon also may have spurred Oregon doctors to address other end of life care options more effectively. In one study Oregon physicians reported that, since the passage of the Death with Dignity Act in 1997, they had made efforts to improve their knowledge of the use of pain medications in the terminally ill, to improve their recognition of psychiatric disorders such

Abbreviations: PAS, physician assisted suicide; DWDA, Death with Dignity Act; FLSMT, forgoing of life-sustaining medical treatment; WTWER, withholding or withdrawing of life sustaining medical treatment without the patient's explicit request; VAE, voluntary active euthanasia

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as depression, and to refer patients more frequently to hospice.[4]

Although Bonnie Steinbock concedes that the dire predictions of a wholesale abuse of Oregon's DWDA have clearly been proven wrong, she remains sceptical as to whether aid in dying really justifies a sea change in medicine and law. In her paper, *The case for physician assisted suicide: not (yet) proven*, she concludes: ''I am not suggesting that the Oregon law should be repealed. […] My point is rather that before the rest of us climb on the PAS bandwagon, there are many crucial issues to be hammered out. The discussion should continue. At present, the case for legalising PAS seems to me to be still—in the words of the Scottish verdict—not proven.''[5]

The famous Scottish verdict ''not proven'' is usually taken to imply a strong suspicion of guilt, in the absence of sufficient evidence to convict. So what is Oregon's seemingly successful practice of PAS ''guilty'' of? Or, to rephrase the question, why does Steinbock, as she herself puts it, ''remain conflicted''? Apparently, for two reasons. First, partisanship on the issue of PAS makes it extremely difficult to assess the Oregon data objectively. Proponents of PAS interpret the statistics in a strikingly different way from its opponents. And second, there have been several reports about abuses of the Oregon DWDA, suggesting that the existing safeguards do not work. These cases of alleged abuse involve patients who might have been mentally incompetent or clinically depressed. In one of these cases—for example, the one usually referred to as ''Helen's case''—a woman in her mid-eighties with breast cancer had been diagnosed with depression by an internist, but as competent by a psychiatrist. Four additional doctors who were also involved in her terminal care agreed with the psychiatrist and ''considered her psychologically healthy and competent to make medical decisions for herself''.[6] So had the internist's diagnosis of depression consciously and deliberately been ignored, as opponents of Oregon's legislation claim? We do not want to get into this debate. Let it suffice to say that the mere fact that most of the allegations of abuse come from the author of *Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder*,[3] should at least make us pause.[7] What is more, when the British House of Lords visited the State of Oregon to inquire about the reliability of the reporting system and the practicality of the legal safeguards, even the entirely unsuspicious executive director of the Oregon Hospice Association, Ann Jackson, stated: ''Oregon is a very, very small state and we have hospices all over, and they have big mouths! I think if there were any abuses in the law, we would hear of it.''[8]

Although we agree with most of Steinbock's excellent paper, her overly cautious, if not outright disheartening conclusion calls for five critical comments. First, her reference to the old Scottish verdict and her recommendation to other US states not to climb on the PAS bandwagon imply that ''there is something rotten in the state of Oregon''. More specifically, it tacitly assumes that the legalisation of PAS may have put the terminally ill at greater risk. What makes her think, however, that this is really the case? Most likely, the highly controversial claims that there have been a number of abuses in Oregon. Yet even if these allegations were true, we are simply in no position to make the claim that the terminally ill have become more vulnerable since the legalisation of PAS. To demonstrate that, we would need to have at least *two* sets of empirical data: data collected *before* and data collected *after* the passage of the DWDA. Only then would we be in the position to determine whether the terminally ill have become more or less vulnerable. Given that there are no data on the incidence of abuse prior to the legalisation of PAS, we simply cannot claim that the terminally ill are now at a greater risk.[9]

Second, given that her advice that other US states should wait for some more years before jumping on the PAS bandwagon is solely based on the highly controversial claims of abuse, it is simply unwarranted. Does she really believe that waiting for, say, another seven years will actually resolve the controversy over Oregon's DWDA? That is highly unlikely! There will always be claims of abuse. If no one else will, Wesley J Smith will make sure of it.[7] Thus, if other US states that are currently considering legalisation of PAS, such as Vermont and California, were to follow her advice, they would, in all likelihood, never get a chance to pass their own version of a DWDA. Personally, we hope that Vermont and California will follow Oregon's lead. These states might, however, indeed be well advised to implement some additional legal safeguards, such as a mandatory assessment by psychiatrists for all patients seeking PAS. Implementing more stringent safeguards will by no means guarantee that there will not be any claims of abuse, but it may at least reduce the number of wrongful allegations.

Third, by relying on dubious claims of abuse and by attempting to dissuade other US states from following Oregon's lead, Steinbock makes it virtually impossible to prove the case for PAS. If controversial cases are considered as evidence against the practicality of PAS, and if other states are not permitted to enact their own DWDA, how can she possibly expect an ''American verdict'' on the case of PAS?

Fourth, Steinbock appears to be inconsistent in applying her own approach. At the outset, she emphasises that policy decisions ''should *not* be based solely on individual cases, heart wrenching though these may be''. Yet her entire argument is based on two ''individual cases'', in which abuse *might* have occurred! As already mentioned, there is ample reason to doubt that the cases Steinbock highlights did involve any abuses. We do not deny, however, that abuses may, indeed very likely will, occur. No system is foolproof and no legislation without risk. It is, of course, a tragedy if someone capable and desirous of enjoying life meets an untimely death as a result of abuse of PAS legislation, in Oregon or elsewhere; but discovery of such cases would not serve to demonstrate that the legislation is flawed. Abuses will occur under any legislative regime, whether PAS is permitted or not. Steinbock asks us to assess the need for and the risks of PAS. We endorse her call. She, however, has not done this. Which brings us directly to our fifth and final critical comment on her paper.

Although Steinbock adopts a consequentialist approach and suggests that ''we need to assess the *need* for PAS, and weigh this against the *risks* of mistake and abuse'', she does not give us any indication as to how we are supposed to balance the two. Suppose, for the sake of the argument, that the opponents of PAS are right and that there have indeed been several cases of abuse of Oregon's DWDA. Let us say that among the 208 cases of PAS there have been five such cases. Would these five cases outweigh the remaining 203 cases? If not, how about 10 such cases? 15? 20? How many cases of abuse ought to be tolerated before we can say with certainty that the risks of PAS outweigh the need for PAS? Unfortunately, we are not told.

At least in theory, the answer to the question of how many abuses can be tolerated could go like this: we should tolerate the same level of abuse in PAS that we tolerate in forgoing life sustaining medical treatment (FLSMT). Although it is often ignored, FLSMT is as prone to abuse as PAS. Just as the poor, the elderly, the disabled, and the clinically depressed can be subtly pressured into PAS, so they can be subtly pressured into FLSMT. And just as physicians concerned about the costs of medical treatment can subtly pressure

patients into requesting PAS, they can subtly pressure patients into requesting FLSMT.[10] As far as we can see, there is simply no justification for treating the risks of FLSMT any differently from the risks of PAS. After all, in PAS as well as in FLSMT, the result is a non-voluntary death.

Unfortunately, treating the risks of PAS and FLSMT alike is easier said than done. In order to tolerate the same level of abuse in PAS as in FLSMT, we would need to have reliable data on the number of abuses occurring in the context of FLSMT. We do not, however, have any such data. Also, establishing the number of deaths resulting from subtle pressures to forgo life sustaining medical treatment, it seems, is simply impossible.

A more practical way to determine an acceptable level of risk in physician assisted suicide is by relying on comparisons of the incidence of withdrawing or withholding life sustaining medical treatment without the patient's explicit request (WTWER). Although no one fails to mention the notorious ''1,000'' cases of life terminating acts without explicit request found in the Netherlands,[11] hardly anyone acknowledges the existence of the same practice in other countries. A US study conducted in 1998 found—for example, ''that in 15.3 per cent of cases, the patients were not involved in the [end of life] decision but families wanted the patients' lives ended. This lack of involvement even occurred in cases where the patients were conscious and could have participated in the decision.''[12] Similarly, an Australian survey conducted in 1997 ''revealed that in more than 20 per cent of cases Australian doctors hastened their patients' death by withdrawing treatment without an explicit request''.[13] In Italy and Sweden, ''more than 50% of all end of life decisions, whether for competent or incompetent patients, were discussed with neither the patient nor with relatives''.[14]

A recent study comparing end of life decision making in six European countries—Belgium, Italy, Sweden, Denmark, Switzerland, and the Netherlands—indicates that permitting PAS or voluntary active euthanasia (VAE) may actually decrease the number of cases in which doctors withhold or withdraw life sustaining medical treatment without the patient's explicit request: ''In all countries other than the Netherlands and Switzerland, the incidence of life terminating acts without explicit request of the patient was higher than the incidence of physician assisted suicide and voluntary euthanasia on request of the patient. Perhaps an open debate and a tolerant policy are not that bad after all.''[15]

Although we do not have comparable data for Oregon, it is not unreasonable to assume that legalisation of PAS may have appreciably reduced the number of doctor's decisions to WTWER. If so, we certainly have to take this into account when balancing the benefits and risks of legalising PAS. Given that a statistically significant reduction in the number of WTWER might very well tip the scales, we should encourage US states considering legalisation of PAS to conduct surveys measuring the current incidence of WTWER. This way, we can reliably determine whether the legalisation of PAS has or has not reduced the incidence of WTWER.

Let us conclude by advancing some additional suggestions as to how the case for PAS might possibly be proven. As already indicated, assessing PAS is a comparative matter: we need to know what potential there is for abuses under a particular legislative regime, as compared, not only to other legislative regimes that permit PAS, but also to others that ban it. All means of regulating end of life medical treatment have their risks of abuse. Doctors may collude with one another, or maverick doctors may act alone; incompetent patients may pass for competent, and relatives and others might attempt to coerce patients into a premature death. We know that PAS occurs even in jurisdictions that forbid it, but we have little idea of how often it is abused (indeed, how often *involuntary* euthanasia, or murder disguised as PAS or involuntary euthanasia occurs). Since we do not have these comparative statistics—they are, by their nature, difficult to gather—we are not in a position to assess the risks of PAS. Nor are we in a position to assess the risks of *not* having PAS. We note, however, that it is at least possible that legalising PAS reduces the number of abuses, for several reasons: because patients are able to remain rational longer when they do not fear losing control over the timing and manner of their death (recall that more patients request and receive lethal barbiturates than actually use them); because the stricter oversight reduces the potential for abuses, and because doctors respond to requests for PAS by improving end of life care.

Thus, answering Steinbock's call for an assessment of the risks of PAS requires more data than we have. Moreover, even if we are able to gather the relevant data, there remains hard *conceptual* work to do, in weighing the risks against the benefits of the legalisation. How do we go about assessing the risks? What weight are we to place on the loss of hours, days or weeks of life, when we are talking about the life of an incompetent, perhaps delirious, patient who is suffering from pain or depression (all of which are sufficient to make PAS illegal)? This is an extremely difficult question; we note here only that anyone who believes that it is appropriate to take quality adjusted life years into consideration in making decisions about medical treatment seems committed to thinking that these kinds of factors do make a difference here. Against the loss of lives, we need to weigh the benefits gained by PAS, measured in peace of mind, enhancement of autonomy, and forgone pain and suffering. Once again, we have little idea how to quantify these things. Yet assessing the risks and benefits of PAS requires that we have answers to these questions.

Steinbock is right to hold that attention to heart wrenching cases is not sufficient to make the case for PAS. Yet she does not provide us with any suggestions for proceeding. Here we have provided a few such suggestions. Assessing PAS requires a great deal of work, both empirical and conceptual. In the meantime, we have no evidence at all that it is riskier to permit PAS than to forbid it.

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Clinician-Patient Interactions About Requests for Physician-Assisted Suicide

A Patient and Family View

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Background: Responding effectively to a patient request for physician-assisted suicide (PAS) is an important clinical skill that involves careful evaluation. Clinician responses to PAS requests, however, have only been described using data obtained from clinicians.

Objective: To describe qualities of clinician-patient interactions about requests for PAS that were valued by patients and their family members.

Participants and Methods: Intensive qualitative case study involving multiple longitudinal interviews conducted prospectively with patients pursuing PAS and with their family members and retrospectively with family members of deceased patients who seriously pursued PAS. The study setting was community based. Participants were recruited through patient advocacy organizations, hospices, and grief counselors. A total of 35 cases were studied: 12 were prospective and 23 were retrospective. Study procedures involved semistructured interviews that were audiotaped, transcribed, reviewed, and analyzed by a multidisciplinary research team.

Results: Three themes were identified that describe qualities of clinician-patient interactions that were valued by patients and family members: (1) openness to discussions about PAS; (2) clinician expertise in dealing with the dying process; and (3) maintenance of a therapeutic clinician-patient relationship, even when clinician and patient disagree about PAS.

Conclusions: These patient and family accounts reveal missed opportunities for clinicians to engage in therapeutic relationships, including discussions about PAS, dying, and end-of-life care. Clinicians responding to patients requesting PAS need communication skills enabling them to discuss PAS and dying openly, as well as expertise in setting reasonable expectations, individualizing pain control, and providing accurate information about the lethal potential of medications.

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FOR PHYSICIANS and other clinicians who care for patients with life-threatening illnesses, responding to a patient's request for physician-assisted suicide (PAS) is an important clinical skill. Although Oregon is the only state to have legalized PAS, patients in every state report that they think about PAS, and physicians in every state discuss PAS.[1] In a national survey involving 988 terminally ill patients, 60% of patients supported PAS in a hypothetical situation, and 10% had seriously considered PAS for themselves.[2] In physician surveys, 18% to 24% of primary care physicians and 46% to 57% of oncologists stated that they have received a request for PAS.[3-5]

When a patient asks for PAS, how should a clinician respond? Experts agree that an initial clinical response should include the following: the clinician should ask why the patient is interested in PAS, explore the meanings underlying the request, assess whether palliative care is adequate (especially in addressing depression), and revise the care plan to respond to the patient's concerns.[6-11] Since PAS requests may not persist, these initial clinical responses are extremely important. Beyond the initial response, however, there is controversy about whether clinicians should disclose their own moral beliefs about PAS, offer sedation for refractory symptoms or intolerable suffering, or provide a prescription for PAS in a state where it is illegal.[12-15]

Although expert recommendations for responding to PAS requests presume that clinicians possess communication skills and palliative care expertise, little empirical research has been conducted to identify exactly what skills and expertise are required.[7-9,11] Previous surveys of physicians suggest that the most prominent concerns for patients considering PAS are nonphysical concerns about dying, such

PARTICIPANTS AND METHODS

DESIGN

A qualitative design was chosen for this study because of the lack of empirical data describing how clinicians respond to requests for PAS. We used semistructured interviews to yield data that we analyzed and developed into a description of important qualities of clinician-patient communication about PAS from the perspectives of patients and their family members.

SAMPLE

The sampling frame for this study included patients and family members who were actively seeking information and access to PAS because we wanted to describe the process of planning and implementing PAS. This sample includes a self-selected group of patients and family members who sought out advocacy organizations that specifically help patients organize a PAS. Therefore, the sample is limited to those patients and their families who were engaged in assessing PAS as a concrete option for determining the timing and circumstances of their death.

We focused on 2 groups of participants: (1) a prospective cohort of patients who were currently pursuing PAS (and their family members); and (2) a retrospective cohort of family members who had been involved with a patient pursuing PAS. Based on other qualitative studies, we estimated that about 30 families would provide enough data such that additional data would fail to contribute further to explaining the phenomena being studied, a condition called *theoretical saturation*. Our sample size of 35 families was not intended to be a comprehensive view of all patients seeking PAS, but it was adequate to describe this particular group of patients and family members. Thirty of the 35 cases occurred in a state where PAS is illegal.

PARTICIPANT RECRUITMENT AND INFORMED CONSENT

We asked intermediate sources such as patient advocacy organizations that counsel persons interested in PAS, hospices, and grief counselors to introduce our study to potential participants. Our intermediate sources gave detailed written information statements describing the study to prospective patients with life-threatening illnesses (and their family members) who expressed a serious interest in PAS and were attempting to obtain medications for PAS. Our definition of *family member* included unmarried partners and close friends. We also asked our sources to mail information statements to family members who had been involved in PAS. These information statements asked potential participants to call our office if they wished to participate or ask questions about the study. One investigator (H.S.) spoke with each potential participant to explain study procedures, answer questions, obtain verbal informed consent, enroll participants, and collect demographic data.

To protect the confidentiality of our participants, no written consent forms or any other forms with identifying data were maintained by the investigators. The detailed information statements described the purpose of the study, interview procedures, and participants' right to refuse to answer questions or to withdraw from the study at any time. Prospective patients had to have an ongoing relationship with a case manager and medical care providers to be eligible for the study. Subjects in the prospective cohort were informed verbally and in the written information statement that if interviewers identified a serious medical or psychiatric issue that was not being addressed, or if a psychiatric issue was causing decisional incapacity, investigators would inform the patient's case manager and we would discontinue interviews with the patient and his or her family. These issues were discussed with participants in detail, and informed consent was obtained verbally before each interview. Also, the interview guide for prospective patients contained a statement assuring patients that we were interested in their concerns and decision-making processes and would continue to follow them regardless of whether or not they ultimately decided to pursue PAS. Study procedures were reviewed and approved by the Institutional Review Board of the University of Washington, Seattle.

DATA COLLECTION

We conducted multiple qualitative, semistructured interviews with patients and family members. Five investigators conducted interviews, and the same investigator interviewed all participating members of a family. The prospective cases included interviews with 12 patients and 20 family members. The retrospective cases included interviews with 28 family members concerning 23 patients. In total, we conducted 159 interviews with 60 participants about 35 families (12 prospective and 23 retrospective), resulting in 3613 pages of transcripts. The interview guide included questions about (1) patient and family interactions with health care providers regarding PAS requests, (2) how these requests were evaluated, and (3) the provider's involvement with PAS implementation. We asked participants to provide details about the manner of death and any complications of a PAS attempt. We also asked family members to describe their personal reactions to the PAS request and subsequent events. Other topics were covered but are not included in this analysis.

CODING AND ANALYTIC METHODS

All interviews were audiotaped and transcribed, with identifying data deleted. Each case was discussed at weekly meetings by the multidisciplinary research team, representing medical oncology, palliative care, health services, psychology, anthropology, psychiatry, geriatrics, and bioethics. The analytic approach was based on grounded theory, which involves open coding (a process of examining, compar-

as loss of control and loss of dignity.[3,16] Yet a qualitative study of physicians who dealt with PAS requests indicated that physicians felt least competent in addressing existential suffering.[17] Judging by these studies in the medical literature and anecdotes in the lay press,[18-20] it appears that the nonphysical concerns about dying that prompt patients to consider PAS are issues that many physicians feel poorly equipped to address.

We conducted an intensive qualitative interview study with patients who seriously pursued PAS and with

ing, conceptualizing, and categorizing data), followed by axial coding (a process of reassembling data into groupings based on relationships discovered in the data) and, finally, selective coding (a process of identifying and describing central phenomena in the data).

We coded patients' and family members' first-hand accounts of interactions with clinicians, and did not code hearsay accounts. Examples of primary codes include "reasons for pursuing PAS," "interactions with health care providers," and "planning for death." The interviewer and another investigator independently coded all transcripts, compared coding, and resolved disagreements in coding. Significant coding discrepancies were discussed at the weekly team meeting.

Axial coding involved all sections of transcripts assigned the primary code "interactions with health care providers" for the analysis presented here. Two investigators (A.L.B. and H.S.) developed secondary codes that classified clinician-patient interactions. The intent of the secondary coding was to characterize clinician-patient communication about PAS, non-PAS end-of-life issues, and palliative care. Secondary codes were used to classify subject perceptions of PAS conversations; clinician knowledge, attitudes, and skills; and clinician-patient relationship issues. Examples of secondary codes include "explicit PAS discussion," "clinician willingness to discuss dying," and "clinician empathy." The secondary codes were refined through review with the multidisciplinary research team. At this stage, participants' statements about what they valued in their clinician's response to a PAS request, or what they wanted but did not get in their clinician's response to a PAS request, emerged as central issues.

Finally, in selective coding, the key phenomena that related to the issue of how patients and family members wanted clinicians to respond to PAS requests were identified. Our analysis at this step differs from some other grounded-theory studies in that we did not attempt to build a completely new theory of clinician-patient communication. Rather, we focused on patient and family perceptions of clinician-patient communication in order to describe key attributes of communication about PAS. The 3 major themes we report are the products of this analysis. These themes were shared among patients and family members and did not differ between prospective and retrospective subjects.

To enhance trustworthiness, each step of the analysis was reviewed in weekly investigator meetings to ensure that the analysis was anchored to specific identifiable data from transcripts. ATLAS.ti software was used to facilitate data management and analysis.[21] The themes from this analysis were presented at a meeting of our patient advocacy intermediate sources (a group that includes clinicians, advocates, and family members), and we received verbal and written feedback confirming the validity of our analysis. No major changes were made as a result of this presentation.

their family members. The primary study objectives were to describe the reasons that the patient was pursuing PAS, the narrative of events leading to death, and interactions with physicians and other clinicians. This article reports our findings about interactions with clinicians.

We asked our participants to describe their conversations with their physicians and other medical clinicians about PAS. From these data, we identified themes that describe qualities of clinician-patient interactions about PAS that patients and family members valued. In describing what patients and family members valued when discussing PAS, we hope to provide guidance for clinicians faced with these difficult conversations, regardless of their willingness to provide PAS or its legal status.

RESULTS

PARTICIPANT CHARACTERISTICS

We studied 35 cases of patients who pursued PAS and their family members. **Table 1** and **Table 2** give the characteristics of the participants. Table 1 also lists the manner of death and where the patients obtained their lethal prescription. For the prospective cohort, the mean time between the first interview with patients and death was 10.6 months (range, 0.1-30.6 months). For the retrospective cohort, the mean time between the patient's death and the first interview with a family member was 20.2 months (range, 2.4-49.5 months).

THEMES

Most patients and family members could recall the PAS discussions with their clinicians in substantial detail. Their first-hand accounts of clinician interactions regarding a PAS request provide important data about their perceptions of clinical care related to PAS. The themes summarize what patient and family members valued in communicating with clinicians about PAS.

Openness to Discussion About PAS

Patients and family members highly valued clinicians who were willing and open to discussing PAS. When they encountered a clinician who was willing to discuss PAS, they felt able to disclose many concerns about dying. They also felt lucky because they knew PAS was controversial. As one family member put it, what she wanted was "another sane adult" who could "talk in terms . . . that remove the taboo from the process" by giving "a real, clear picture of possible approaches without advocating [PAS]." The following counterexample underscores the importance of clinician openness to discussion about PAS.

> I know the physician that we had—the conversations were a struggle with him because we couldn't talk about hastening the death. So there was, like, a part of us that we could not talk about, which made our questions limited. So it was like we didn't have access to information that would have allowed our conversations to be more full and more fully informed.

Patients and family members attributed clinician unwillingness to discuss PAS to a variety of reasons. Some clinicians were unwilling to discuss PAS because it was illegal. These clinicians behaved as if discussions of PAS in and of themselves were illegal and dangerous. One patient observed that "all [my physicians] talk about is the legality of it," and another concluded that clinicians "have

Table 1. Patient Characteristics

Characteristic	Prospective Cases (n = 12)	Retrospective Cases (n = 23)	Total Patients (N = 35)
Age, mean (SD) [range], y	72 (10) [60-89]	66 (19) [33-99]	68 (16) [33-99]
Female	6	11	**17**
White	12	23	**35**
Marital status			
Married or living with partner	4	14	**18**
Divorced or separated	1	4	**5**
Widowed	5	4	**9**
Never married	2	1	**3**
Education			
High school or less	1	3	**4**
Some college	6	5	**11**
Bachelor's degree	4	3	**7**
Graduate degree	1	5	**6**
Unknown	0	7	**7**
Underlying illness			
Cancer	8	14	**22**
AIDS	1	4	**5**
Neurologic	1	4	**5**
Other†	2	1	**3**
Received hospice and/or home health care	7	18	**25**
Manner of death			
Physician-assisted suicide‡	5	13	**18**
Euthanasia§	2	5	**7**
Underlying illness	4	4	**8**
Self-inflicted gunshot wound	0	1	**1**
Still alive at the end of the study	1	0	**1**
Source of lethal prescription			
Primary or specialty care provider	6	13	**19**
Friends or acquaintances	3	6	**9**
Did not obtain medications	2	4	**6**
Declined to report	0	1	**1**
Health insurance			
HMO (includes Veterans Affairs)	2	9	**11**
Fee for service	3	8	**11**
Medicaid only	0	3	**3**
Medicare + supplemental	5	2	**7**
Medicare + Medicaid	2	1	**3**

*Data are given as number of patients, except for age. Data for prospective cases are reported from 12 patients and 20 of their family members; data for retrospective cases are reported about 23 patients by 28 of their family members. AIDS indicates acquired immunodeficiency syndrome; HMO, health maintenance organization.

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

‡Death by physician-assisted suicide included patients who had medications that they voluntarily ingested with the primary intention of ending their lives.

§Death by euthanasia included patients who asked clinicans or family members to administer a lethal dose of medication with the primary intent of causing death. Patients who died by euthanasia either were competent at the time of death but not able to self-administer medications, or were decisionally incapacitated but had specifically requested that medications be administered if they lost decisional capacity.

Table 2. Family Member Characteristics*

Characteristic	Family Members of Prospective Cases (n = 20)	Family Members of Retrospective Cases (n = 28)	Total Family Members (N = 48)
Family members interviewed per case, mean (range)	1.7 (1-4)	1.2 (1-3)	1.4 (1-4)
Relationship to patient			
Spouse or partner	5	10	**15**
Daughter	5	10	**15**
Son	6	2	**8**
Other in-law	1	3	**4**
Friend	3	3	**6**
Age, mean (range), y	51 (31-82)	52 (29-74)	51 (29-82)
Female sex	11	17	**28**
White race	20	27	**47**
Education			
High school or less	3	0	**3**
Some college	5	3	**8**
Bachelor's degree	5	4	**9**
Graduate degree	6	15	**21**
Unknown	1	6	**7**

*Data are given as number of members, except for age.

to hide their feelings about [PAS], so as not to jeopardize their careers." In other cases, patients and family members reported that the topic of PAS provoked a strong emotional response from clinicians that made further conversation awkward. For example, one family member described a neurologist who was "so adamant that PAS was a terrible thing and the wrong thing to do . . . it was kind of awful." Another subject described a physician's reaction to a PAS request as "protective [of himself] . . . not at all sympathetic or comforting." One patient described how she could detect that her oncologist became "really uncomfortable" talking about PAS or "anything" about dying, and she changed the subject for him. She said, "I learned that he's a baseball fan and much more comfortable if I change the topic to baseball. . . . It's awful when you have to try to make them feel comfortable, but that's the way it is." Other clinicians seemed to want to maintain a biomedical focus. One family member said, "They won't talk to you about [PAS] even as a possibility. It's like, 'I know that happens, but—what about let's do the chemotherapy.'"

The value of clinician openness to discussing PAS went beyond this topic alone. Patients felt that a clinician willing to talk about PAS might also be willing to discuss other worries, fears, and vulnerabilities about illness and dying. As one patient said, "Everything was laid out on the table. Oh, you bet, yeah. Because he can't help you—nobody can help you if they don't know what's going on in your life." In a different case, a family member described how her father's relationship with the caseworker from an advocacy organization provided a different dimension of care than he received from his oncologist. The family member said, "It provided a place where he could talk about his illness. He didn't talk about hastening his death [because he was prepared and did not think it was time]. He's just describing to them what's going on with him and so on. But it's good to have a place like that."

Thus, patients may use talking about PAS as a gateway to talk about dying.

> It's not that she [my friend, the patient] doesn't want to [talk about dying]; that's the sad thing. She's sitting here holding all of this stuff in, and to me the most important events in your life are your transitions, your birth and your death . . . the beginning and the end of this physical existence. But you can't talk to your doctor about it without them getting all weird, [thinking] that you're suicidal or something.

This patient, during her own interview, wept as she described her frustration trying to talk to one of her doctors. She said, "You're trying to get a doctor to sit down and listen to you . . . but they never, ever get the overall picture." Her clinicians' unwillingness to discuss PAS resulted in missed opportunities to connect with this patient's deepest concerns, which included her quality of life, her prognosis, and her suffering.

Another value of clinician openness is that it facilitated a complete evaluation of a PAS request. Participants described clinicians who were willing to assist patients and families but who avoided discussing PAS openly or explicitly. In these cases, the clinicians fulfilled PAS requests with little evaluation. One patient's wife said, "My husband, with the advice of a doctor friend that lives in [another state], went to his cardiologist . . . And he told the doctor that he needed Seconal. And this doctor has known my husband for a long time, and all he said was, I trust you have a good reason, and gave it to him, a prescription for it." In this case, a family member obtained a prescription for PAS from a physician who had never met the patient. This is an extreme case in our sample but it is not unique. Two other patients in our study obtained prescriptions without any medical evaluation. In one of these cases, a family member found that after a visit with the patient's oncologist, the necessary prescriptions had been tucked into her purse without her knowledge. Clinicians who deal obliquely with PAS requests may miss opportunities to fully evaluate and understand the issues underlying the request.

Expertise in Dealing With the Dying Process

One important type of clinician expertise was the ability to describe the natural history of illness and care options in the last days of life. Patients and families were extremely sensitive to the ways in which clinicians talked—or avoided talking—about these issues. A woman with metastatic ovarian cancer found that she could not get information from her oncologist about how she would die, so she went to a medical library and read a textbook on gynecologic cancer. What she learned was that dying of ovarian cancer was "long, protracted, not very happy . . . organ failures or blockages or blood poisoning or pneumonia, and it takes a whole combination of things to finally just be fatal." Although she confronted her oncologist with this information, she left without reassurance that she could avoid a long, agonizing death. She concluded that PAS was probably the least worst way for her to die. In a different case, another patient was told by his physician that in "all the AIDS cases in the city, it was the worst thrush they'd ever seen." His partner reported:

> Our doctor was like, you do not want to die of thrush, and then kind of described how it would happen. Basically, he said the thrush would grow and shut off your esophagus, so that you'd not be able to swallow . . . [my partner] would drool constantly and end up starving to death, because he wouldn't be able to pass any food down. The doctor said, "You don't want to die like that." And that's when [my partner] decided to do a hastened death.

The patient and his partner interpreted the physician's statements, which did not include a medical response to fears of drooling and starving to death, as a tacit endorsement of PAS as the best option in their circumstances. Before this conversation, the patient was already considering PAS, but this conversation marked a turning point in his interest.

Another valued type of clinical expertise was defining reasonable expectations about dying and then delivering the care necessary to fulfill those expectations. One woman with lung cancer was very suspicious of doctors and hospitals, believing that "cancer is big business." She declined anticancer therapies but was willing to explore palliative care options. Her physician referred her to hospice, and her experience there made her rethink her commitment to PAS:

> Before Thanksgiving, I went over to the hospice [an inpatient unit] for respite care. It's a wonderful place. It's absolutely wonderful. Unlike a hospital, you don't see any uniforms; you are not No. 14 or No. 12; you are a person. The only thing that resembles a hospital is the bed and the tray table. Outside of that, there is absolutely nothing that resembles a hospital. There is no noise of anyone being in pain. It's wonderful; it really is. [My] main concern is to be pain free, and they do take care of that.

She ultimately died of progressive cancer at home with hospice care.

Another case of a patient with advanced acquired immunodeficiency syndrome exemplifies what can happen when clinicians overpromise a "pain-free" death:

> The physician encouraged [stopping total parenteral nutrition] as a nice way to go and said that that would be probably a 3-week process, maybe 4 at the most, but probably 3. "That's a very pleasant way to die. It's pain free." . . . We went in and out of the emergency room 3 times over pain in the last 2 weeks of his life . . . and he had great, agonizing, lower abdominal pain through it all. So I felt real cheated about that. It wasn't this quiet, pain-free existence. . . . If you're going to make a guarantee that a person is really not going to be in pain, you need to make sure that they're not. And if you don't think that you can make sure, you shouldn't promise.

When dying proved to be neither quiet nor pain free, the patient and his partner began to plan a PAS.

A third type of expertise was individualizing pain control to meet patient goals. In one case, the absence of this expertise led to a death by a self-inflicted gunshot wound. The patient had painful bony metastases to his spine and was "on 800 milligrams of morphine a day. Besides all the Roxicet he could manage to keep down." His oncologist referred him to hospice for better pain management. However, the patient and his wife found that their hospice providers had an agenda about pain con-

trol that did not allow for the fact that his top priority was to maintain a sense of control over his situation.

They put him on a morphine pump. It took him a couple of days to adjust it, and they were extremely caring. They hovered. They just about drove him up the wall. [They said,] "We're going to kill your pain." Well, they killed his pain. He was unconscious for almost 24 hours. Flat on his back. He had not been able to lay on his back. He was totally out of it. He got up the next day and he said, "I feel like Ray Milland's 'Lost Weekend.'" [That movie was about] an alcoholic who just went through all sorts of, just, DTs and, you know, it just—really hell on wheels. And that's exactly how my husband felt. He said, "I can't think; I can't do this."

The next morning, the patient fired the hospice and discontinued the pain regimen. "Once the hospice people had knocked him for 1 loop, he wasn't going to let it happen again," explained his wife. The following day, the patient warned his wife not to follow him outside, where he positioned himself out of sight and shot himself in the head. The hospice nurse wrote in her bereavement card, "At least he got one good night's sleep," to which his wife responded, "I almost went through the ceiling."

A final type of expertise involved clinician knowledge about the lethal potential of medications. In cases in which clinicians had this knowledge and were willing to provide a prescription for PAS, patients and families were reassured that if they ultimately decided to implement a PAS, it would be successful. As one family member said:

The psychiatrist that [my husband] saw said that he didn't understand why my husband needed to be in hell anymore, or myself, and that he was seeing that a lot had been tried, and he thought that [my husband] should be able to end his life if he wanted. So he began describing the correct pills, and so there—and so then when he had it, I remember there was just a huge relief on both of our parts and deep gratefulness to that person.

In other cases, however, patients or family members received instructions from clinicians to increase doses of morphine and diazepam to hasten death that proved to be incorrect. One family member recalled how a hospice nurse, with explicit instructions from the physician, taught him how to unlock an intravenous patient-controlled analgesia device and how to administer a lethal dose of morphine. "They told us that within 3 to 4 hours his heart would stop and it would be over . . . Very specific. And we were never told any alternative. We were never told it might not work. . . And of course, it didn't work." After 12 hours, the patient woke up, and his partner spent days frantically searching for information and support. The patient finally came up with the idea of dissolving secobarbital tablets in saline and injecting them intravenously. The family member called the physician and hospice nurse for help, but "when I asked what went wrong, they had no idea." Despite these frustrations with clinician expertise, patients and family members remained genuinely appreciative of clinicians' efforts on their behalf.

Maintenance of a Therapeutic Patient-Clinician Relationship, Even When Patient and Clinician Disagree About PAS

Every patient and family member in this study recognized that asking for PAS was a special request that went beyond the usual boundaries of a clinician-patient relationship. Maintaining the clinician-patient relationship was made possible by clinician openness to discussion and clinician expertise. Also, it involved explicit negotiation about the roles of each party in the relationship as well as clinician self-awareness of emotional vulnerabilities. Patients and family members were relieved and reassured when clinicians made an explicit commitment to assist with PAS in some way. However, when clinicians declined to participate and were able to set clear boundaries about their role, as in the example below, they could still maintain an important relationship with a patient and family member.

My internist simply will not do [PAS], not just because of fear of the law, [but] because his approach is he will not end life. . . . I adore my internist who, when he had more time, used to make house visits to see [my late husband when he was dying] and pep him up. Wonderful. So I love this guy; I really do, even though I disagree with him on this issue. I love him, and I respect him as a doctor.

When patients had had meaningful relationships with their clinicians, family members often wanted some closure with them. In our study, this occurred both when clinicians assisted PAS in some way and when clinicians evaluated and discussed PAS but did not assist in any way. For example, members of one family went to the physician's office the day after their mother's death: "We took some living flowers and a card and a sweater . . . [my mother] sent him her favorite sweater; it was a men's sweater anyway. So we saw him, and that was our closure with him." In another example, one patient's physician was sympathetic to her situation, said she would help as much as she could with maximizing comfort, but also said that she could not provide a prescription for PAS for legal reasons. The family obtained a prescription elsewhere, and made plans for PAS, all the while maintaining close contact with the physician. The family called this physician the day after the patient died of PAS, in part to reassure the physician that she had done a good job. "[We] told her it went well and that she hadn't failed. She had cried. I mean she wanted to totally help us and just felt her hands were tied." Thus, the therapeutic aspect of a clinician-patient relationship does not rest on a clinician's willingness to provide a lethal prescription.

One case illustrates the importance of clinician self-awareness of emotional needs and vulnerabilities in maintaining a therapeutic relationship. As the family member put it, their physician "lacked boundaries." This physician had an intense relationship with the patient that included daily telephone calls and home visits, and on the night the patient attempted PAS, the physician implemented a backup plan after oral medications failed. After the patient's death, the family member reported that "[the physician] would go over to the hospital to see a patient, and she'd call me at 10 o'clock PM and say she

wanted to come over [to our house] and sit in the room where he died and 'hang out.' And I'd say no, and she'd come over anyway." After a couple of these incidents, the family member wrote the physician requesting that they have no further contact because he felt burdened by these requests. Regardless of their own beliefs about PAS, clinicians can maintain therapeutic relationships with their patients when open communication, expertise, and appropriate boundaries are present.

COMMENT

This report describes clinician-patient interactions from a unique set of data involving 35 patients (and their family members) who seriously pursued PAS. The qualitative methodology we used provides an in-depth, behind-the-scenes look from the patient and family perspective on how clinicians dealt with requests for PAS. From more than 3600 pages of transcribed interviews, we identified 3 themes describing qualities of clinician-patient interactions that patients and family members valued highly. These themes raise important considerations for physicians and other clinicians about the skills, attitudes, and knowledge needed to handle requests for PAS.

The controversy over the morality of PAS, including surveys of the general public,[22] extensive media coverage of Jack Kevorkian,[23] the 1997 US Supreme Court decision,[13,24] and medical journals,[6,25] has created a context for discussing PAS that highlights potential conflict between patients and clinicians. Discussions about death and dying—even without PAS—engender intense emotions in patients, family members, and clinicians.[26,27] It comes as no surprise that many clinicians would rather avoid the topic altogether. Our finding that clinicians had varying degrees of openness to discussion about PAS (theme 1), and broader discussions of dying as well, leads us to wonder whether published surveys of physicians actually underestimate the degree to which patients wish to talk about PAS. When physicians say that their patients never ask about PAS, it may be because they block the discussion. Maguire[28] has described how clinicians block and avoid the concerns that patients with cancer have about dying. Our data suggest that PAS is another patient concern that is frequently blocked.

The medical literature on responding to PAS requests acknowledges that these discussions can be uncomfortable and awkward, characteristics that can be barriers for physicians. But what has not been described in the literature is the way that patients in our study used discussions about PAS as a starting point for discussions about dying that ranged far beyond PAS. In a medical culture that views death as a failure, dying patients may feel as if they have failed.[29] Physician-assisted suicide provides a different kind of end-of-life story for patients, one that emphasizes individual values and personal choice,[30] and data from patients in Oregon underscore the importance of autonomy for patients who choose PAS.[1] Our data indicate that PAS can serve as the entry point for discussions that go beyond the right to die, to explore concerns about dying. Recognizing this can enable clinicians to probe beyond the issue of PAS. In addition to asking, "Why are you considering PAS?" it might be useful to ask, "How do you want your death to go?" or, "How do you want it to look?"

A lack of openness to discuss PAS may result in a "don't ask, don't tell" policy for both patient and clinician. Clinician openness may be crucial for patients to feel comfortable in extending a PAS discussion beyond technical medical issues, such as a lethal prescription, and toward difficult topics such as dying and suffering, which can constitute an unacknowledged "elephant in the room."[31,32] The lack of communication that we observed about PAS suggests that a kind of collusion may occur that enables both patient and clinician to avoid difficult subjects, as has been described in other situations.[28,33] Collusion may allow a clinician to avoid a PAS discussion that is awkward and difficult, but at the cost of missing an opportunity to reassure patients that their concerns will be addressed and that they will not be abandoned.[34,35] Our data suggest that the presence of collusion may be a marker for inadequate clinician communication skills or clinician discomfort with dying, and may lead to the provision of a lethal prescription for PAS without patient evaluation.

Patients and family members also valued expertise in dealing with the dying process (theme 2). The specific aspects of expertise that our subjects mentioned included communication skills, setting reasonable expectations, individualizing pain control, and knowledge about the lethal potential of commonly used medications. The combination of cognitive and affective skills encompassed in these observations resonates with other work describing curricular needs for clinicians in end-of-life care.[36] Our work also underscores the need for clinicians to have both specific content knowledge in discussing and managing dying and patient-centered communications skills in order to respond to requests for PAS.[37,38]

The combination of openness to discussions about PAS and expertise in dealing with the dying process are what make a continued clinician-patient relationship possible when a patient pursues a hastened death. Our data suggest that even for this highly selected group, a therapeutic clinician-patient relationship may be as or more important to patients and family members interested in PAS than a lethal prescription. When the patients in this study approached their clinicians about PAS, they were usually looking for more than just a prescription. They were looking for someone with whom they could build a therapeutic alliance—a person who could act as a sounding board or guide them through the dying process. Although some existing guidelines for responding to PAS requests address the request as a single event, our data emphasize the importance of the process of responding to a request over time in the context of a clinician-patient relationship.

Patients and family members were mindful of the importance of boundaries in therapeutic relationships. Our data show how underinvolvement or overinvolvement by a clinician can be problematic in dealing with patients requesting PAS. These behaviors may reflect the clinician's personal emotions. Block and Billings[9] and Miles[39] have outlined, based on clinical experience and a careful reading of psychological and psychiatric literature, how the personal emotions of clinicians might in-

Table 3. Guidelines for Responding to a Patient Requesting Physician-Assisted Suicide (PAS) Suggested by These Data

1. Address the PAS request explicitly and openly.
2. Ask about what kind of death the patient would like to have.
3. After understanding patient wishes and expectations, offer to discuss how dying could be managed.
4. Check patient perception by asking, "What are you taking away from our talk today?"
5. Remember that the process of building a therapeutic relationship is more important than providing a lethal prescription.
6. Monitor yourself for underinvolvement or overinvolvement in the clinician-patient relationship.

fluence their behavior in dealing with a patient considering PAS. For clinicians, these issues of personal emotion, which may include self-awareness, boundaries, transference, or countertransference, require attention because they can facilitate or complicate the clinical relationship.[40-42] Our findings reinforce other work stressing the importance for clinicians to monitor their own feelings and to establish boundaries in their relationships with patients.

While the strengths of this study are in its detailed, "thick" description of a small group of patients and family members, it also has corresponding limitations. The study participants were a self-selected sample of patients and their family members who were highly motivated to pursue PAS, interested in telling their stories, and physically able to search for and find people willing to help facilitate PAS. Nearly all our participants obtained access to lethal prescriptions despite the illegality. These participants may not be directly comparable to those of other PAS studies in which the patients were enrolled from inpatient palliative care units[43] or had a uniform medical diagnosis.[44,45] In addition, our participants not only exhibited a desire for PAS, as has been studied in other outpatients,[46] but also actively made plans and tried to implement them in order to have a hastened death.

Another study limitation is that we were not able to interview the clinicians involved with our study participants. It is possible that patients and families themselves contributed to the communication issues described here. For example, patients who were secretive about their intention to pursue PAS may not have alerted their clinician to their need to explore a desire for PAS, or they may have colluded with their clinician to avoid discussing PAS.[33]

Finally, the themes we report are based on patient and family member reports of their perceptions of communication rather than on transcripts or videotapes of actual conversations. However, patient and family perceptions are extremely important, and the 3 themes that we describe articulate patient and family member concerns that were present in the majority of interviews we conducted.

Based on this study, we suggest a set of guidelines that clinicians might use when responding to patient requests for PAS (**Table 3**). These guidelines may also be useful for educators who are teaching communication skills that are relevant to end-of-life care.

CONCLUSIONS

Responding to a patient request for PAS is an important, and complex, clinical skill. These clinical discussions occur amid profound moral controversy, the emotions engendered by death and dying, and the technical complexities of contemporary medical care. Our patient and family accounts reveal many missed opportunities for clinicians to engage in therapeutic relationships involving discussions about PAS, dying, and end-of-life care. Clinicians responding to patients requesting PAS need communication skills that will enable them to discuss PAS and dying openly, an ability to talk about dying in a patient-centered way, and palliative care expertise. They also need expertise in setting reasonable expectations, individualizing pain control, and providing accurate information about the lethal potential of medications.

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