

Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families

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ABSTRACT

In 1997, the Oregon Death with Dignity Act was enacted, allowing a physician to prescribe a lethal dose of medication for a competent, terminally ill patient who requests one. In 2000, we conducted single, semistructured, in-depth, face-to-face interviews with 35 Oregon physicians who received a request for a lethal prescription. The interviews focused on physicians' perceptions of patients who requested assisted suicide, the reasons for the request, and the reactions of their families. The interviews were audiotaped, transcribed, and analyzed using qualitative techniques. Physicians described requesting patients as having strong and vivid personalities characterized by determination and inflexibility. These individuals wanted to control the timing and manner of death and to avoid dependence on others. These preferences reflected long-standing coping and personality traits. Physicians perceived that these patients viewed living as purposeless and too effortful, and that they were ready for death. The requests, which were forceful and persistent, could occur at any point after diagnosis of the terminal illness, and were paralleled by refusal of medical interventions including palliative treatments. Many family members were reluctant to support these requests until they recognized the strength of the preference.

INTRODUCTION

THE DEATH WITH DIGNITY ACT, enacted in 1997, legalized physician-assisted suicide in the state of Oregon. The law authorizes a competent, terminally ill patient to receive a prescription for a lethal dose of medication from a physician for the purpose of self-administration.¹ The patient must make one written and two oral requests over a period of 15 days, and a prognosis of less than 6 months of expected life must be confirmed by a second physician. Between 1998 and 2002,

129 individuals died by legalized assisted suicide, accounting for 1 in 1000 deaths in Oregon.^{1,2}

Surveys of Oregon physicians have contributed to our understanding of the reasons that patients request assisted suicide.²⁻⁶ These surveys have been comprised of close-ended questions developed from experts' opinions about the reasons patients request lethal prescriptions. Because these domains of inquiry were not derived from physicians' actual experiences with patients requesting assisted suicide under legal conditions, some important factors motivating patients

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may not have been identified. In addition, such surveys do not permit detailed descriptions of interactions among health care practitioners, ill patients, and their families around requests for assisted suicide. In the process of conducting a mailed survey of Oregon physicians about assisted suicide,³ we asked each physician survey respondent who had received a request for a lethal prescription to participate in an in-depth interview. We present here qualitative analysis of these interviews. Results describe the physicians' perceptions of these patients, the reasons for the requests, and the reactions of family members.

METHODS

In 1999, we conducted a mailed survey of Oregon physicians regarding experiences with the Oregon Death with Dignity Act.³ Of 2649 who returned surveys, 144 physicians indicated they had received a request for assisted suicide. Seventy-three physicians initially returned a letter indicating that they were interested in being interviewed. When contacted, 23 were no longer interested in participating or did not respond to a second mailing, 13 had not actually received a request for assisted suicide, and 1 willing physician lived in a region of Oregon too remote for an in-person interview. One physician served as a practice interviewee. Of the 35 physicians interviewed, 8 were women; 13 were from the Greater Portland area, 10 were from medium-sized towns, and 12 were from small-sized towns. Fourteen interviewees practiced in internal medicine or one of its subspecialties, 13 in family practice, 6 in surgery or one of its subspecialties, 1 in therapeutic radiology and 1 in neurology. Thirteen were unwilling to prescribe a lethal prescription under the Act, 1 was unsure, and 21 were willing.

The physicians were offered \$50 for their time and interviewed once either at their home or office between May and August of 2000. Each interview lasted between 45 and 90 minutes. All interviews were audiotaped and transcribed. Potentially identifying material was removed from the transcripts. The study was approved by the Institutional Review Board of the Portland Veterans Affairs Medical Center and all participants gave written informed consent.

The interview guide was finalized after the first eight interviews were reviewed by research team

members (reproduced in part in Appendix A). New themes that emerged in subsequent interviews were discussed in an ongoing manner among team members and pursued in subsequent interviews. The approach to analysis combined techniques from ethnography (descriptive, ordered analysis of data) and grounded theory (development of theories of the process of assisted suicide requests).^{7,8} Transcripts were read initially by L.G., and the constant comparative method of developing themes (open coding) was used.⁹ Subsequently, all three coauthors read all transcripts and proposed additional themes. Relationships and patterns across categories were explored and the most important themes identified by L.G. Other coauthors reviewed the determinations regarding important themes and concurred on all accounts. All 27 interviewees who were quoted were sent a draft of the manuscript and 21 responded. All confirmed that we accurately captured their thoughts and observations and that the quotes preserved confidentiality of the physician, patient and family. So that the reader may independently assess the strength of our theories, several tables with comments relevant to the theme are presented.

RESULTS

Who requests physician assisted suicide?

Physicians described patients requesting assisted suicide as "independent" or as valuing independence (Table 1). The word "independent" sometimes indicated that the patients did not need help with their activities of daily living or that they were physically active and energetic individuals before the onset of their illness. "Independence" was also used to describe the person's life values and philosophy, indicating the importance of self-determination; or relational characteristics, indicating self-sufficiency and a lack of reliance on other people. Indeed, these patients dreaded the thought of being dependent on others. Physicians perceived that for these individuals the dying process presented too much risk of becoming dependent, through pain, mental deterioration, living in a nursing home, becoming emotional, or losing the ability to talk, walk, or control ones bowels and bladder.

Physicians also portrayed these individuals as "determined." The physicians described general

TABLE 1. INDIVIDUALS WHO REQUEST ASSISTED SUICIDE ARE INDEPENDENT

<i>Physician^a</i>	<i>Comments</i>
E	She had a very strong personality. She was very active and independent; that was a real important part of her life . . . Her own personal philosophy dictated that communication and self-determination are the most important things in her life.
H	He was kind of a crusty old guy.
M	He was a physically active man and it has been a big struggle for him to give up all of his physical activities.
T	He was an autonomous person.
V	She was very independent.
X	A typical rural resident in the sense he is tough, macho, in control-of-himself-and-everything-else-kind of fellow.
CC	She didn't want to have anyone take care of her. She didn't want anyone washing her butt. . . . self determination was really important to her.
DD	He was a very strong-willed sort of patriarchal type of figure. He was a very independent soul . . . really sort of carried his whole family along in terms of this process. The idea of physical suffering had been an issue with him. But probably less of an issue than the concern about independence and loss of independence (Patient 1). He was a fellow who had been a very active physical guy. He was a teacher, retired, but had been very physically active, and he did not want to become dependent (Patient 2).
EE	He was living in this apartment. He had no intention of going into any of those "g.d. nursing homes" (Patient 1). It was an issue of not wanting to be taken care of (Patient 2).
FF	Well, he was very independent. He was a gentleman. He was a very, just a nice, a very well-spoken gentleperson, who would have a twinkle in his eye. Often he would kiss my hand. I would shake his hand and then he would kiss my hand. And then, as often, I found him charming . . . His son might have said, "He is controlling, not just independent." . . . Well it was very hard for him to accept personal care, not wanting help bathing and showering beyond the time when it was probably unsafe for him to be getting in the shower by himself. He was pretty adamant about his decision about where he would live and how his money would be spent.
HH	And she was a tremendous wit. She was clever. She was a feisty (elderly) lady, she walked all over town by herself. And from the outset, very intellectual, smart, open and cooperative. And frank about what provoked the most fear in her was the fact that she would no longer be able to be independent.

^aPhysicians were assigned consecutive alphabetical letters for identification purposes.

inflexibility in how these individuals approached complex challenges. As Physician CC noted: "And the question is, some people you know, their mind sets just won't allow certain things to happen. People get into jams, they get themselves into corners and they can't, you're not going to change them when they're 70 years old." Adjectives used to describe them included self-directed, in charge, strong-willed, and stubborn. As Physician W summarized: "She was a wonderful personality. Very, very strong personality. She was very sure about what she wanted . . . Very, very opinionated."

Independence and inflexibility often placed the person in a central role in their social sphere, as "patriarchs" or "queen bees." As Physician X explained about a patient disfigured by his malignancy: "It was embarrassing for him in terms of his tough, macho, partly Native American image

and as head of the household, and he has always been the leadership, and in charge." In some situations, the patients' independence and inflexibility resulted in a social life with self-imposed restrictions.

Physicians portrayed the patients as having vivid and engaging but also strong and forceful personalities. Adjectives used to describe these patients included interesting, memorable, unusual, likeable, amazing, passionate, eccentric, and self-involved, but also as crusty, reclusive, demanding, or solitary odd ducks whose views did not always mesh with the philosophy of hospice. Physicians often used qualifying adverbs such as "extremely" and "very" in describing these personality features, suggesting that in the physicians' experiences, patients were at the far end of the spectrum regarding these characteristics.

Physicians found these patients both challenging and likable, with only one patient described as unlikable because he was difficult and manipulative. As Physician Z, who had received several requests, summarized:

And they're up front. Sometimes they're a real pain in the ass because they are very sort of noncompliant in some ways or directive. They're very demanding and so they are not necessarily the easiest patients to deal with. But you know that you have a partner when they finally make a decision to go along with whatever treatment it is that you've prescribed. They'll do very well because they'll be out of the hospital in one day instead of eight days . . . And they won't bother you with little details. And if there is a complication, they say, "Alright, you told me about that." So I think that's a distinction. They're thoughtful because they have processed this idea.

How do patients request assisted suicide?

With regard to their communication style, these patients were described as outspoken, articulate, and forthright (Table 2). Their requests for assisted suicide reflected the patients' determined nature; they were described as adamant, forceful, and persistent. Physicians reported that the patients were single-minded, uncompromising, and without doubt or ambivalence about their preference for assisted suicide.

Individuals persevered in the requests, even when physicians were unwilling to participate in assisted suicide. As Physician S noted: "I never gave him hints that I would change my mind (about writing a prescription)," and he (the patient) said, "I am going to come in and I am going to try to convince you."

These individuals' responses to physicians presenting alternatives to assisted suicide ranged from polite disinterest to expressions of irritation and annoyance. Physician K said: "I learned very quickly that the patient's agenda is to get the medication. When I tried to talk them out of it, or to really assess their motivations, then they perceived me as obstructionist and became quite resentful of that." Some patients appeared more willing to consider palliative or hospice care only after the issue of assisted suicide was settled. Physician DD summarized: "They're really not

able to talk or think about things like hospice care until they know that this other issue has been taken care of. It is almost a kind of condition for them to get palliative care to know that there is something to let them out of it if they get stuck."

When some patients did consider alternatives, it was because the physician could address current physical suffering or future fears, and the individual was comforted by the physician's reassurances that he/she would "be available" to the patient throughout the illness.

When do individuals request a lethal prescription?

Physicians described these individuals as acknowledging the terminal nature of their illness, and approaching death without denial or avoidance. As Physician N observed: "He knew he wasn't going to outlive his tumor, number one. And he'd had it, I think. He was getting near the end. I think he had had it for two years, so we both knew it was getting to the end of that."

The timing of the request for assisted suicide varied. Some asked almost immediately after receiving the diagnosis of a terminal illness. Physician DD recounted: "I mean it was absolutely clear as a bell the moment he knew what his diagnosis was what he wanted . . . And I don't think we have talked for more than 5 minutes before he wanted to talk about physician-assisted suicide. That was right at the front of his mind." Others underwent both life-prolonging and palliative treatments before making the request or deciding to use the prescription. Despite variation, eventually these individuals began to refuse life-prolonging and palliative treatments, ranging from surgery, chemotherapy, radiation therapy, tamoxifen, hospice, pain clinic referrals, social work referrals, and food and fluids. As one physician noted after offering a patient several options: "He did not want to listen to any of it."

The course of illness influenced whether individuals requested assisted suicide and how persistent they were. For many patients, the disease progressed too rapidly for them to adjust to disability. Physician M speculated: "I think these three people got hit completely out of the blue, got blindsided by a fast moving malignancy. It was just too much to take in too short of time." Although terminally ill, many were still able to present themselves as decisive and determined because they were not yet robbed of the force of

TABLE 2. REQUESTS FOR ASSISTED SUICIDE ARE CLEAR, ADAMANT, AND UNWAVERING

<i>Physician^a</i>	<i>Comments</i>
C	Her ability to encapsulate her perspective, point of view, and sort of sense of right was really impressive . . . She was a wonderful debater . . . She communicated extremely well. She was very articulate (Patient 1). She was extremely outspoken. She knew what she wanted; she made up her mind (Patient 2).
D	He made it clear that that was his intention.
E	Because this lady is so determined there is no way we can talk her out of it. She was very adamant.
F	He was often a decisive person.
H	He was very straightforward, and it was very easy to get a history from him. He was very easy to understand. He did not mince words or anything like that . . . He wasn't going to take any grief from anybody. He just said exactly what he felt. You know, one of these guys from (small logging town).
K	If you try to talk someone out of this by exploring other options, patients find that to be patronizing. They would say "I don't want that. I already know what I want. So why spend all of this time trying to convince me on something I have already decided I don't want?"
L	She was fairly clear about her wishes . . . She had made a decision.
M	She was unwavering in her decision.
O	He was a very intelligent individual. He knew exactly what he wanted. It was very clear . . . He was a straightforward, intelligent, competent individual. He knew what he wanted and understood fully what the disease was. And that is what he wanted to do.
T	He did not meet the requirements because he did not have less than six months to live. So I counseled him again and again and again, and he said again, and again, and again that he demanded this . . . He made his own choices.
W	. . . he was very clear about it.
CC	And we had talked about all the other things and I could tell she was politely listening to me and willing to go through it (treatments and evaluations) so she could get her way . . . She was not actually doing that bad. She had all the therapy she could possibly have. She was a very, very nice lady, very intelligent, knew exactly what she wanted to do. She respected everything we talked about but she knew what she wanted . . . But the fact was she was terminal and she had made up her mind.
DD	He felt for himself, it was such a slam dunk. I mean he knew exactly what he wanted and what he should have and he just could not understand why everybody was making such a big fuss about it. He was a very forthright person (Patient 1).
EE	She had already decided that is what she was going to do. Very unusual and sort of single-minded purpose . . . I was saying, "Gee, it is unusual to have somebody with that degree of determination and ferocity. Unusual to have somebody who really, if you gave them open ended questions . . . would just sort of cut you off."
FF	The patient was extremely adamant about this was what she wanted and she would find someone to help her do that.
GG	Some of them were not as direct, but at least two stand in my mind as being very direct, very forceful and brought up multiple times. It was such a direct, you know, "I want you to administer a lethal injection." You know, "When I'm ready, when I'm done hunting." (Note: The patient wanted to live through one more deer-hunting season.)

^aPhysicians were assigned consecutive alphabetical letters for identification purposes.

their personalities or mental clarity. Physician B, who received three requests, summarized: "They all had fairly good physical capacity and mental capacities, so that they were able and they had clear thinking for a long period of time, out of the ordinary for our hospice patients." Although the disease progressed too rapidly to adjust to disability, the dying process itself was not quick enough. "Often it is the disease that is slightly more indolent, so that the patient is taking too

long to die, and that's where the desire for physician-assisted suicide originates" (Physician K).

Why do individuals request a lethal prescription?

The theme of control was predominant in physicians' descriptions of why their patients requested assisted suicide (Table 3). Having or being in control was a life long value and philosophy of these individuals, a current coping strategy

TABLE 3. INDIVIDUALS REQUEST ASSISTED SUICIDE TO CONTROL THE DYING PROCESS

<i>Physician^a</i>	<i>Comments</i>
K	Exerting his will over his last moments was what was important . . . It's very much a sense of wanting to control the time and manner of death and prevent future suffering.
L	I've been impressed then with three out of four people, clearly people who viewed control over their lives as a priority . . . that is how they lived their lives . . .
N	He had some brain mets and he was just starting to fall. And I think that he had fallen off the porch. And he saw himself as losing control of his ability to talk, his bowel function and stuff like that and thinking that it is what he did not want . . . And he just wanted to be in control at the end.
R	(Regarding several requests.) But these were individuals who wanted control of their lives, and it was mostly control issues. And they sort of started that right up front. It had nothing to do with the care that they were getting. And they would return to it and return to it and you could say, "Well you know we are doing all we can. And we are making this commitment to you. And we will try to take care of you." But you know they sort of fixated on ending their lives from the get go.
S	His family said what he really wants is control, he doesn't want to lose control.
V	She had spoken with them (her friends) completely about her death and how she wants everything to be.
W	He just wanted absolutely nothing to do with the mental cognitive deterioration . . . he did not want anything to do with it. He wanted to turn off the lights while he was still mentally functioning and could do so and had control of things. And control is the issue.
Z	At the beginning he said, "I want to make one thing perfectly clear. I need a doc who is going to give me a lethal prescription because I want to be in charge." And they are not people who go to a doctor and say, "Okay, tell me what to do, doctor." Clearly.
CC	I think her big fear was loss of control. She wanted to control things right up to the end. She wanted to plan it. She wanted things to go the way she wanted it. And she didn't want to wait. She did not want to take a chance at waiting until it would not be under her control any more. She was very in charge. But you know she was . . . most people like that can be little bit difficult to deal with and the like. She was not like that at all.
DD	(I struggled) with what our roles were. You know who was in charge? And I have always sort of felt like patients should be in charge, but he was in charge of a process that I was not that familiar with . . . The issue with him from beginning to end was control.
GG	A lot of people in this area are very self-sufficient. They pride themselves on chopping their own wood . . . he had been working in the woods all his life and supporting his family and very much in control.

^aPhysicians were assigned consecutive alphabetical letters for identification purposes.

and a future goal. The wish for control was part of a pervasive coping style:

. . . so she was a control person. You know, we are talking big time control. . . . You know, "I am in charge here." She sort of self-directed her medical care . . . It was a control issue, not a pain issue . . . "I want to be in control of my destiny. I don't want to go out as, you know, incontinent, in pain, crying, you know tearful person. I want to go out with some dignity" (Physician P).

In addition, control was a value in and of itself:

She just felt this was not dignified at all for a woman who had been in control all of her

life. And she knew the end was near anyway. And she said, "I want to do it on my terms. I want to choose the place and time. I want my friends to be there. And I don't want to linger and dwindle and rot in front of myself" (Physician M).

For some patients, exerting control became synonymous with dying by lethal prescription, such that one could not happen without the other. Two stories encapsulated the extreme position. Physician W recounted:

When I saw her she was very, very weak and very dehydrated. And again, I told her, I said, "Gee, you're within a couple days probably of losing consciousness just from dehydration, and we could make sure that

you just slept and did not suffer and it would just be a short time." She had the 15-day wait and she had 4 days before the medicine could be prescribed. And I told her that I didn't think she would be able to do that unless she could solve the nausea and dehydration that she would last for 4 days consciously and to take the medicine. And she sort of struggled into a sitting position, asked her husband to get her a glass of water, and said, "I'll get the fluids down somehow." And sort of forced . . . See, this is the paradox, this is where you learn that lesson about the control issue—she actually reversed the natural process to prolong her suffering, in order to be in control, to push the button herself.

Physician K told a similar story:

I was surprised by the amount of power and personal will a patient would exert to take his own life. My patient was hours from death, in a nursing home, on a high dose of valium. But he awoke from the valium haze and said, "I want to go home and take the medication." We offered him whatever dose of valium it took to keep him essentially sedated until he died. But he called his sister to come and take him home. "I want to do it," he said. "I want to die in my own bed by this medication."

In contrast to the energy and focus these individuals brought to their request for assisted suicide, they often had a sense of ennui and tedium regarding their remaining life. Many seemed tired and played out: "It was not like she could not enjoy any given minute, it was like she was done. She'd read a book, she'd tell you what was in it, she'd laugh and then she would say 'I really wish I did not have to keep doing this, but I will as long as I have to'" (Physician C). Although physicians reported searching for a mood disorder, they did not perceive these individuals to be depressed. Rather they perceived a sense of being ready, of lack of clear purpose and having nothing to look forward to, combined with the burden of daily hassles and too much effort and struggle:

He told me that if all you can look forward to is your next enema, and you don't even

like that much, what is the point of living? (Physician J).

It was more that she really did not want to hassle it anymore . . . it was just "Why am I doing this? Each day was worse than the day before. If you get oxygen you can breathe better, but still tomorrow is going to be worse than today even with the oxygen . . ." (Physician C).

There was a great deal of variation in the role of current physical symptoms as reasons why individuals requested assisted suicide. For some, symptoms were difficult to control: "She was truly miserable. She was at the end . . . She was only comfortable when unconscious" (Physician M). Reasons for requesting assisted suicide more often had to do with future fears of suffering rather than current suffering: "He was very fearful of what the end might be like. He was worried about the pain. He was worried about the shortness of breath. And yes, he was very upfront about being afraid to die in misery" (Physician S).

Physicians also commented about the patients' distaste at burdening others with their care. This concern appeared even when family members professed to take pleasure and find meaning in caring for the patient.

Views of family members

Physicians reported that when family members were available, they were informed of and involved in the patient's decision to pursue assisted suicide. They described variation in the views of family members regarding the patient's request for a lethal prescription. Some families were supportive, and, recognizing that the patient very much wanted this option, were understanding and ready. Other families were uncertain. Some family members opposed assisted suicide initially, but became convinced by the patient that this was the correct course. Physician AA recounted a patient's request:

When he asked me he caught his wife by surprise . . . He just said, "I'm gonna, I want to take advantage of the assisted, of the Death with Dignity Act." And his wife was in the room with him and she turned around and said, "What are you talking about?" And she, they got into a little discussion

right there. "Don't you think I have something to contribute to this conversation?" and "We've been married almost 50 years" and "I think I should have something to say here." And they actually called back and she called the next day and said, "We've had a good talk about it and I think he's right and I support him." She just said, "This is what he wants and I think it is best for him."

Others continued to oppose the option of assisted suicide, but acknowledged that it was the patient's right. They struggled with the idea, were slow to accept it, and were reluctant or anxious about the process. As Physician C noted about a daughter:

She struggled a lot. Her husband was the family member who was the most opposed, still is. None of these family members wanted this to happen but they also wanted to support their Mom and they knew that she was just really solid about this. So that was her point of view, was that "I'm going to do what my Mom wants me to do for her."

Physician E, referring to a son, said that:

He was somewhat sympathetic to the patient although, you know he was not very excited about the physician-assisted suicide. But then he talked to the patient and apparently they had a very heated conversation. But eventually the son became an advocate because his mom really wanted to do it.

Even when family members disagreed strongly, they tried to accept the idea. Physician P summarized: "They weren't going to overpower her and stop her from doing this. But I think they were bewildered and a little hurt by that, you know, by the decision."

Physician X told of a meeting with a wife:

And basically I spent an hour with her as I heard her describe in exquisite detail how mad she was at him. And how mad the family was at him. And how they disagreed with this decision. And how they did not like what was happening at all. But ultimately it had been his choice, and although they did not like it, they were trying hard to accept it. They were very, very mad at him because they thought it was selfish of him.

And they were mad at him because they liked him.

DISCUSSION

When the Oregon Death with Dignity Act was enacted in 1997 there was very little empirically based research to shed light on why patients request assisted suicide. Experts in mental health, ethics and end-of-life care speculated that patients were motivated to pursue assisted suicide because of depression, untreated pain or other symptoms, lack of social support, financial concerns, a desire not to burden their families, and poor relationships with their health care practitioners. Some suggested that families, burdened by care of dying patients, might coerce vulnerable ill relatives into an early death.¹⁰⁻²³

Studies to date have challenged some of the concerns. In a mailed survey, Oregon physicians reported that the most common reasons patients made these requests included fear of loss of independence, poor quality of life, readiness to die, wanting to control the circumstance of death, seeing continued existence as pointless and fear of burdening others.³ The Oregon Health Division (OHD) has annually surveyed all physicians who prescribed a lethal medication under the law.¹ They reported that the most common reasons patients requested assisted suicide included loss of autonomy, inability to participate in activities that made life enjoyable, loss of control of bodily functions, and concern for burdening others.^{1,2,4-6} Lavery et al.,²⁴ in a qualitative study of patients with acquired immune deficiency syndrome (AIDS), reported that desire for physician-assisted death was influenced by concerns about disintegration as a result of symptoms and loss of function as well as progressive diminishment of opportunities to sustain close personal relationships.²⁴

Our qualitative study amplifies the importance of previously identified factors and allows theorization about their interconnections. As seen through the eyes of their physicians, these patients had an unusually strong desire to remain independent and in control. The value placed on control and independence was a pervasive coping style that preceded the decision about assisted suicide, and even the terminal illness. This coping style was manifested as a determined, inflexible approach in attempting to access a lethal prescription, examining alternatives to assisted suicide, and convincing others of the correctness of

this course. Having control allowed avoidance of dependence, which was intolerable for many patients. Patients appeared to project their own dislike of being dependent onto their families by assuming that families would experience their care as burdensome. The burning desire for independence and control is maintained against a background of fading energy, waning engagement in the world, and a conviction that future moments can only be worse in quality than the present.

Other studies support that wanting to maintain control and not burden others, is important for many dying patients.^{25,26} The physicians we interviewed, many of whom had extensive clinical experience in end-of-life care, used language to suggest that in their experience these patients were exceptional in the degree to which the valued control, abhorred dependence and marshaled their limited energy to pursue assisted suicide even in the face of physician and family reluctance. The Oregon law, with safeguards that require documentation of the persistence of the request, assessment by a consultant physician and, in some cases, assessment by a mental health professional, may screen out those individuals who are not able to maintain this determination over time. The degree to which these patients are unusual may offer some explanation as to the rarity of assisted suicide even when legal.

Our discussions with physicians yielded more limited insights into the viewpoints of families who supported their family members' decision to pursue assisted suicide. These discussions did underscore, however, that there is variation in views within families. Many are slow to accept the patients' decision for assisted suicide, but when confronted with the strength of the ill person's preference, advocate for the family member despite their discomfort. Even when families opposed the decision, they recognized that the patients' request was autonomous and consistent with lifelong values. Little is known about how these families adjust to the death, whether the patient is successful or not in obtaining a lethal prescription.

There are several important limitations to this research. First, as qualitative research, the results are theoretical, possibly biased, valid only for the group studied and therefore potentially not generalizable.^{7-9,27} Potential bias was addressed by having both the informants as well as coauthors review and verify the material. The information about patients and families comes through their physicians, and is likely influenced by the physicians' points of view. For example, a physician's description of

the persistence and determination of a patient in seeking assisted suicide may be influenced by the importance of this behavior to the physician. For physicians potentially willing to prescribe, the perception that the patient is determined may increase the physician's confidence that the decision is not impulsive or transitory. For physicians unwilling to prescribe, the persistence of a request challenges the practitioner to find alternatives.

These data suggest several ways in which care for patients who request assisted suicide might be improved. The health care team must recognize the difficulty these patients may have trusting others who care for them and their need to be treated with great respect. These patients may need to maintain more interpersonal distance than patients who benefit from warmer and more personal care. Although physicians should attempt to find alternatives for patients requesting assisted suicide, responding with strong arguments to dissuade may be counterproductive and lead to power struggles with patients who are very sensitive to power and dominance in relationships. Frank, open discussion is apt to be more effective than that which the patient perceives as overly optimistic. The clinician should acknowledge how important control is for the patient and explore how the patient's sense of control can be maintained. The clinician should examine the entire burden of life events which could impact on the patient's sense of control.

Although a substantial proportion of patients change their mind about assisted suicide with improved palliative care, for some the very thought of more care, which reinforces their sense of dependence, may be problematic. Instead of conceptualizing the patient as needing more palliative care, the physician should consider focused care which is not overwhelming to the patient. Although the clinician cannot alter the fact that the patient is dying, he may be able to impact those aspects of the dying process for which the patient has special dread. Finally, although practitioners may wish to maintain standards on such issues as cleanliness and safety, these patients may require different standards if making the patient safe and clean results in restrictions and care they find abhorrent.

In summary, future grounded studies of patients' requests for assisted suicide should include measures of control and independence. They should be constructed to reflect the persistence of requests over time, and include measures of the strength of the requests. Physicians' perceptions of patients who pursue assisted suicide

may be useful in developing recommendations for how physicians might optimally interact with patients around these requests.

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APPENDIX A. INTERVIEW GUIDE QUESTIONS

- Tell me about your relationship with the patient before the request for assisted suicide and what sort of person he/she was?
- How did your discussion about assisted suicide start?
- Why did the patient want a lethal prescription?
- What kind of interactions did you have with the patient's family, and how did they feel about the request?

