

The Oregon Death with Dignity Act: Results of a literature review and naturalistic inquiry

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Abstract

The Death with Dignity (DWD) Act, a physician-assisted suicide statute, was initially adopted in Oregon in November, 1994 and became operational in 1998. The purpose of this study is to: 1) determine the nature and form of the empirical literature on the Oregon DWD Act; 2) describe the effects of the DWD Act on Oregonians with disabilities according to the empirical literature; and 3) present opinions held by a group of Oregonians with disabilities about the DWD Act and its effects. A literature review and focus group were conducted for this study. Thirteen empirical studies and 11 state annual DWD reports were included in the literature review. Review of the empirical literature on DWD in Oregon reveals a number of potential concerns, including inadequate demographic profiling of DWD requesting patients, inadequate mental health evaluations, insufficient duration of physician-patient relationships, potential inaccuracy of the six month prognosis, and inadequate exploration of alternative treatment. These concerns suggest that the DWD reporting system may be inadequate and lack sufficient safeguards. The focus group revealed that there are multiple facets to the DWD issue. Within the disability community, there does not seem to be unequivocal support for one viewpoint over another. © 2010 Elsevier Inc. All rights reserved.

Keywords: Assisted suicide; Oregon; Death with dignity; Disability

The Death with Dignity (DWD) Act, a physician-assisted suicide statute, was initially adopted by Oregon voters in November 1994 by a margin of 51% to 49%. Implementation of the Act was delayed by a court injunction until October 1997 and in November 1997, Oregonians voted on a measure to repeal the Act. The repeal was defeated by a margin of 60% to 40% [1]. The DWD Act allows competent Oregonians aged 18 or older with a terminal illness that will lead to death within 6 months to take their own lives by self-administering a lethal medication that has been prescribed by a physician [1].

Information about the DWD Act is maintained by the Oregon Department of Human Services, Public Health Division (OPHD) [2]. The Act requires that attending physicians send forms developed by OPHD to the Division's Center for Health Statistics [3]. In addition, OPHD must annually review a sample of records and generate and make available to the public an annual statistical report of aggregated information collected under the Act. According to the OPHD website,

the Division "is responsible for providing the public with accurate information about the impact of the DWD Act" [4].

DWD has been a controversial topic within the disability community for many years [5]. Even the various terms "physician-assisted suicide," "assisted suicide," "aid in dying," and "death with dignity" are controversial. Some authors have described the development of alternative descriptions, phrases and euphemisms to make the issue more palatable or cloak more loaded terms [6,7]. Despite these concerns, we use the term "death with dignity" because it is used in the Oregon statute and the purpose of this article is to examine the Oregon experience.

The aim of this article is to answer the following three research questions:

1. What is the nature and form of the empirical literature on the Oregon DWD Act?
2. What are the effects of the DWD Act on Oregonians with disabilities according to the empirical literature?
3. What opinions do Oregonians with disabilities hold about the DWD Act and its effects?

For this article, we limited the definition of disability to preexisting impairments or chronic conditions present prior to a terminal illness.

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Methods

We conducted a literature review and a focus group with a purposive sample of Oregonians with disabilities.

Literature review methods

The literature review was conducted to determine if there was published empirical research that assessed the impact of the Act on Oregonians with preexisting disabilities. First, we obtained copies of each DWD report issued by the Oregon Public Health Division from 1999 through 2008. Each DWD report includes an annual and cumulative description of the demographics of DWD participants (including age, race, sex, marital status, education, residence, and underlying illness) and descriptions from physicians regarding patients' end-of-life care, end-of-life concerns (i.e., why patients chose DWD), the DWD process (including whether the patient was referred for a psychiatric referral), the timing of the DWD event, whether the health care provider was present during DWD, if the patient experienced complications, and the use of emergency medical services. Results of comparison studies contained in DWD annual reports and subsequently published in a peer review journal are reported in the peer review literature review results.

Second, we searched the Ovid MEDLINE, PsycInfo, and Google scholar databases using Oregon, DWD, and disability terms (Fig. 1). Duplicates between all the searches were eliminated leaving 13 unduplicated peer-reviewed journal citations that reported empirical data.

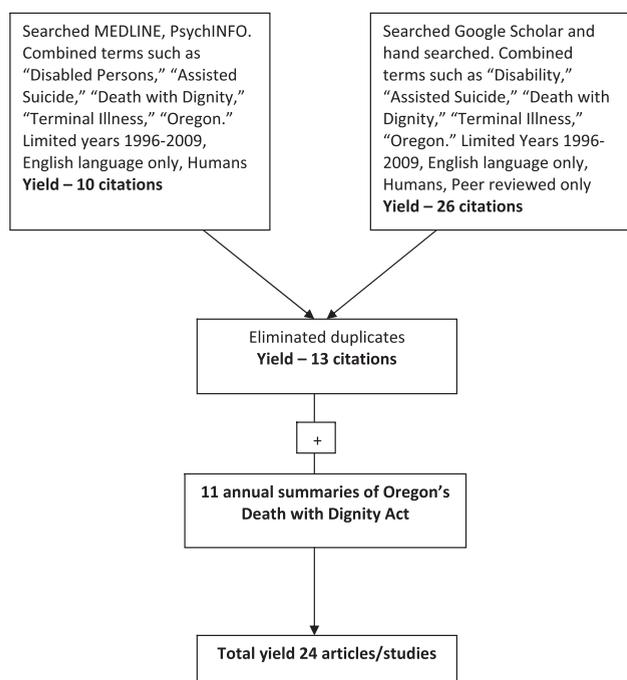


Figure 1. Literature search results.

Focus group methods

The goal of the DWD focus group was to explore previously identified concerns in the DWD literature and generate new knowledge about views of DWD.

Participants

Potential participants were nominated by a disability program coordinator and Center for Independent Living staff to include a range of individuals with physical or sensory disabilities. Participants were recruited using a neutrally worded e-mail invitation to participate in a discussion of Oregon's DWD Act. Twelve individuals participated in the focus group. Table 1 contains the participants' demographic information.

Data collection

Data collection occurred at a focus group meeting in a Portland, Oregon hotel. Two focus group members participated by phone. Participants signed consent forms and received a \$20 gift card. An Interview Guide was developed for data collection (see Appendix A). The study's first two authors co-facilitated the focus group discussion. Detailed notes were taken by three different staff, compared and integrated.

Data analysis and interpretation

Basic thematic analysis of the data was conducted to summarize responses to the Interview Guide using a constant comparison process [8]. That is, one piece of datum was compared with other data to develop conceptualizations of the possible relations between the various pieces of data [9]. Data for this component of the project were analyzed following an interpretivist paradigm [10] which assumes that people "construct" reality by acting and interacting on their own beliefs and perceptions [11]. The constant comparison process resulted in an interpretive description of DWD within the context in which it is experienced by Oregonians with disabilities.

Participants were asked to provide feedback on a written draft of the results. This member-checking [12] step helped ensure the accuracy of the data and the social validity of the study [13].

Results

Literature review results: OPHD annual reports

In 11 years, 401 persons have died using DWD, according to OPHD surveillance data from the OPHD annual reports. Annual demographic information is summarized in Table 2. Malignant neoplasms were cited as an underlying illness in 82% of DWD patients [14].

After the first year, OPHD obtained data on the functional status of patients requesting DWD. Twenty-one percent of DWD patients were described as completely

Table 1
Focus Group Participant Demographics (N = 12)

Characteristic	No. of Participants
Female	7
Latino/a	1
Race	
American Indian/Alaskan Native	1
Caucasian/white	11
Disability type*	
Physical	10
Vision	4
Other	1
Dwelling type	
Own house	7
Rental house	1
Apartment/townhouse/condo	3
Assisted housing	1
Other household members*	
None	6
Spouse	5
Children	3
Other relative(s)	2
Roommate/housemate	2
Area of residence	
Urban	9
Rural	2
Not sure	1
Education	
Associate's degree	1
Bachelor's degree	2
Master's degree	4
Other graduate degree	2
Some college, no degree	3
Employment*	
Employed full- or part-time	12
Retired	4
Student	1
Income	
\$25,000-\$29,999	3
\$30,000-\$49,999	1
\$50,000 or more	8
Described self as an advocate	11
Age in years	Range: 29-73; mean: 51.8
Years with a disability	Range: 15-60; mean: 35.4

* Multiple responses possible.

disabled at time of death [15]. Subsequent surveillance years did not assess functional status in DWD-requesting patients, although data have been collected on certain progressive disabling conditions, including amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), and Shy-Drager syndrome. According to OPHD, 30 DWD patients since 1998 have had a diagnosis of terminal ALS [14]. In annual reports from 2004 to 2006, OPHD demonstrated that the rate ratio of DWD deaths to all deaths of the same illness was highest for patients with ALS compared with other conditions such as cancer. DWD use was more likely among individuals with ALS (269.5 per 10,000 deaths) compared with individuals with cancer (39.9 per 10,000 deaths) [16].

The DWD Act mandates that a patient interested in DWD make at least two voluntary requests with a minimum

Table 2
Characteristics of 401 DWD Patients in Oregon, 1998 to 2008

Characteristics	N (%)
Sex	
Male	213 (53.1)
Female	158 (46.9)
Age (yr)	
18-54	47 (11.7)
55-64	85 (21.2)
65-74	114 (28.4)
75-84	112 (27.9)
85+	43 (10.7)
Race	
Non-Hispanic white	391 (97.5)
Other race/ethnicity	10 (2.4)
Marital wtatus	
Married	185 (46.1)
Other	216 (53.8)
Education	
Baccalaureate degree of higher	176 (43.9)
Some college	92 (22.9)
≤High school degree	133 (33.2)
Insurance	
Medicare/Medicaid	127 (31.7)
Private	265 (66.1)
Other	9 (2.2)
End-of-life hospice care	
Enrolled	350 (87.7)
Not enrolled	49 (12.3)
Place of death	
Home	377 (94.0)
Long-term care	19 (4.7)
Hospital	1 (0.2)
Other	4 (1.0)
Underlying illness	
Cancer	328 (81.8)
Amyotrophic lateral sclerosis (ALS)	30 (7.5)
Chronic lower respiratory disease	19 (4.7)
HIV/AIDS	8 (2.0)
Heart disease	6 (1.5)
Other illness	10 (2.5)

Based on estimates provided by OPHD 2008 annual report [16].

15-day interim between the first and second requests. This time period is provided for patients to reflect on their decision and for physicians to discuss alternatives and assess capacity and mental stability of the patient making the request [17]. According to the most recent OPHD annual report, in 2008, 59 physicians prescribed lethal medications for 88 Oregon residents; the number of prescriptions provided ranged from 1 to 5 per physician [16,18]. In the same year, the duration of DWD patient-physician relationships ranged from 0 to 916 weeks, with a median duration of 8 weeks; the duration of 19 patient-physician relationships was unknown [14]. The last account of characteristics of DWD-prescribing physicians in Oregon was in OPHD's eighth annual report. These physicians were described as having been in practice for a median of 26 years, with principal medical specialties in family medicine (62%), oncology (23%), and internal medicine (10%) [16].

OPHD annual reports cite end-of-life concerns described by physicians who provide lethal prescriptions for DWD. According to these physicians, the most frequently reported concerns among patients include loss of autonomy (90%), loss of meaningful activities (88%), loss of dignity (84%), and loss of bodily function control (59%) [14]. DWD surveillance over the years has also seen a rise in the number of patients apprehensive about inadequate pain management (cumulative total 95 of 401) or concerned about being a burden to family/caregivers (cumulative total 152 of 401) [14]. Because physicians are not required to be present when a patient ingests lethal medications, OPHD accepts information from physicians based on discussions they had with family members, friends/caregivers, or other health professionals present at patients' deaths. In the second year of DWD in Oregon, OPHD provided data collected directly from family members of DWD patients. Most questions asked of family members were analogous to those asked of physicians; family responses were fairly similar to physicians' as well. For example, loss of autonomy and loss of control of bodily functions were frequently cited as patients' reasons behind DWD participation. However, family members tended to report broader patient concerns about physical suffering (53%) more so than physicians did for concerns of pain (32%) [19]. While OPHD indicates that 94.2% of DWD patients inform their families of their decision [14], the statistics do not mention whether family members were involved in the decision process.

Literature review results: Peer-reviewed articles

We reviewed 13 peer-reviewed journal articles on DWD in Oregon in an effort to obtain information relevant to disability. These studies addressed one or more of the following topics: characteristics of patients requesting DWD, self-reported attitudes toward DWD, health provider attitudes and experiences with DWD, impact of DWD on people with disabilities, views and experiences of family members of DWD patients.

Literature on DWD patient characteristics

Characteristics of patients requesting DWD have been described in 11 journal articles. However, indications of preexisting disability have been difficult to ascertain. For example, Ganzini et al. [20] conducted an assessment of Oregon physicians and DWD. A total of 4,053 physicians were mailed questionnaires; 65% responded. Five percent of respondents (144 physicians) had received requests for DWD and provided descriptions of the requestors. In regard to disability, physicians described 83 out of 143 patients as "confined to a bed or chair for more than half their waking hours." However, the study did not delineate between preexisting disability and disability as a result of a terminal illness.

Similarly, preexisting disability was not established in a study conducted by Chin et al. [21] using first-year DWD data comparing characteristics of deceased patients who did or did not use DWD. The study found that 21% of DWD patients were completely disabled at death compared with 84% of non-DWD patients; patients were matched on age, underlying illness, and date of death [21]. Patients' functional status at time of death was obtained from patients' physicians; preexisting disability was not established. The study concluded that DWD patients have lower odds of complete disability than non-DWD patients. However, it is important to consider the circumstances of death among DWD patients and patients that did not use DWD. Seventy-nine percent of DWD patients did not wait until they were bedridden to ingest lethal medication [21]; thus, DWD patients had relatively higher functional status compared with patients who died as a result of their underlying illness.

Although functional status was not assessed in subsequent years, a study by Sullivan et al. of data from the second year of DWD described the mobility of DWD patients. Twenty-six percent of DWD patients from 1998 and 1999 were described with good mobility, 40% with poor mobility, and 33% with no mobility [22]. It is unknown when mobility limitations developed or whether declining mobility motivated DWD use. However, like Chin et al. Sullivan et al. described patient motivation for DWD use as a result of the need for autonomy and the effort to control the circumstances of death [21,22].

Other studies contained protocols to specifically exclude some types of disabilities. For example, the exclusion of patients with cognitive impairments was a requirement in a study by Ganzini et al. [23] on the prevalence of depression among individuals with either terminal cancer or terminal ALS requesting DWD. In the only study to specifically address preexisting disability, Coombs Lee and Werth stated that none of the 34 individuals who approached a DWD advocacy organization between October 1997 and October 1998 and who died within the year "had a disability other than that secondary to their terminal illness" [24].

Attitudes of people with disabilities toward DWD

Two published studies addressed self-reported attitudes toward DWD among persons with disabilities in Oregon. Prior to implementation of the DWD Act, a survey of 100 patients with ALS from Oregon and Washington revealed that a majority were willing to consider DWD and 36 patients would request a lethal prescription early on (to reserve it for future use) in order to avoid any legal complications in qualifying for DWD [25]. A similar study assessing attitudes toward DWD among members of the Oregon and Michigan chapters of the National Multiple Sclerosis Society found a range of opinions [26]. A total of 505 participants were asked whether they had ever thought of DWD as a personal option and whether certain circumstances

(sociodemographics, health, or psychosocial characteristics) or hypothetical situations (such as experiencing unbearable pain, loss of meaningful activity, extreme emotional distress, or causing financial strain) would influence their decision. Persons with more MS symptoms and those who had been diagnosed with MS within the past 5 years were more likely to have considered DWD than those with fewer symptoms and those diagnosed with MS more than 5 years ago.

Health professionals and DWD

Seven studies collected data from health professionals. According to a survey conducted in Oregon in 1997 by Ganzini et al. [20], approximately 54% of physicians receiving requests for DWD support or strongly support the DWD Act and 27% reportedly cared for 21 or more terminally ill patients in the last 12 months. Internal medicine and family/general practice accounted for the majority of medical specialties [20]. Physicians granted one in six requests for lethal prescriptions, with one in ten requests resulting in death [20], yet 27% of physicians willing to prescribe lethal medications were not confident they could determine when a patient had 6 or fewer months to live [27].

Adequate assessments of DWD patients' psychiatric health are a source of contention among health professionals in the literature reviewed. According to DWD Act provisions, the DWD-requesting patient is referred for a mental health assessment only if deemed necessary by the attending physician. Oregon psychiatrists are divided on the ethical permissibility of DWD—one third of those surveyed believed that DWD should not be permitted. Only 6% of psychiatrists were very confident that a single evaluation would be sufficient for determining whether a psychiatric disorder influenced a patient's request for DWD [28].

A study assessing all annual and cumulative data from ODPH claimed that no increased risk of DWD was evident for patients with psychiatric illnesses [29]. However, after the first year of data collected on the DWD Act, Coombs Lee and Werth [24] cited the lack of information on mental health follow-up and questioned the adequacy with which individuals requesting DWD were referred for psychological evaluations. To date, 38 of the 401 individuals who have undergone DWD have been referred for psychiatric evaluation [14]. A study published by Ganzini et al. [20] indicated that physicians, after having discerned that 20% of their DWD-requesting patients were symptomatic for depression, still thought 93% were competent to make medical decisions. Another study described the perception among Oregon hospice nurses that patients who requested DWD had "a desire to control the circumstances of death," and that other issues such as "depression and other psychiatric disorders, lack of social support, and concern about being a financial drain were ... relatively unimportant" [30].

According to one study of health care providers by Ganzini et al. [20], the reasons for DWD requests included (but were

not limited to) loss of independence, poor quality of life, loss of dignity, perception of continued existence as pointless, loss of meaningful activities, and the need to control circumstances surrounding death. Less commonly reported reasons included perceptions of self as a financial burden and a lack of social support [20,31]. Patients for whom one or more interventions were made (such as pain control, treatment of depression, and social work consultation) were more likely to change their minds about DWD than those for whom no intervention was made [20]. In-depth interviews conducted by Ganzini et al. [32] in another study revealed that physicians perceived their patients' desires for DWD as stemming from the patients' inability to adjust to disability. Physicians noted that their patients were willing to consider alternatives to DWD if given assurance that the physician would be available throughout the illness. Since 1994, Oregonian physicians who care for terminally ill patients report that they have endeavored to improve communication with these patients, increase their knowledge of the use of pain medication, and ultimately improve their ability to care for terminally ill patients in general [27].

Disability and increased risk of DWD

Two studies were identified that addressed the risk of DWD among people with disabilities. Given the limitations of OPHD data, special attention was given to a particular peer-reviewed study comparing the impact of DWD on patients from vulnerable groups (which included people with disabilities) in Oregon and the Netherlands. Among their conclusions, Battin et al. [29] claimed that people with physical disabilities or chronic illnesses were not at increased risk of DWD. According to references cited, the authors based their conclusions about Oregon on available data from ODPH [which do not include general disability identifiers], and, additionally, made inferences based on two studies by Ganzini et al. [20,31], which focused on health provider recollections, and a study by Tolle et al. [33], which obtained cause of death from death certificate data. The Battin conclusion seems to be based less on empirical data than on the belief that the two-physician safeguard protects against prescribing DWD based on disability alone. In another section encompassing psychiatric disabilities, the investigators stated that DWD-requesting patients are not routinely evaluated by mental health professionals and that it is possible that some depressed patients receive lethal prescriptions in Oregon [29].

The other study assessed prevalence and correlates of depression in DWD-requesting patients. In 2008, Ganzini et al. [23] published the results of a cross-sectional investigation on the prevalence of depression in terminally ill patients (including individuals with ALS) that indicated that current DWD practices may fail to protect some patients whose choices are influenced by depression. The study involved direct contact with individuals requesting DWD, and special precautions were taken to foster participation. Among those requesting DWD (n = 47), the study

psychologist found that 15 patients met study criteria for depression and six of these patients thought that depression strongly influenced their preference for DWD. All cases were offered counseling but only one participant agreed. It is unknown whether the remaining cases received mental health consultation outside the study. Of the patients who received a lethal prescription ($n = 18$), three met study criteria for depression and died by lethal ingestion within 2 months of their interview. Aside from ALS, psychiatric impairments, and the exclusion of individuals with cognitive impairments as part of the study protocol, no other disability was mentioned in this study.

Family and DWD

Four studies examined family members or caregivers of persons who use DWD. A study conducted by Fromme et al. [34] compared the prevalence of pain or distress in the last week of decedents' lives as reported by family members at two time periods: prior to the passage of the DWD Act (November 1996 to December 1997) and after implementation of the DWD Act (June 2000 to March 2002). The frequency with which family members reported moderate or severe pain increased from 30.8% to 48% between the two time periods. Investigators attributed the increase to several factors: the "media effect" caused by extensive local and national publicity of DWD; the increasing restrictions on end-of-life care and resources, including inadequate pain management or treatment; and the families' own dissatisfaction with the care and support they and the patient received. A study by Ganzini et al. [23] found that caregivers of DWD patients and DWD-interested patients had lost income because of care giving, had delayed plans for themselves or their families, frequently felt stressed, did not have enough time for themselves, and frequently let their social lives suffer. In fact, 24% of those surveyed were found to have clinical depression [23].

In the same study, Ganzini et al. [23] interviewed caregivers of ALS patients in Oregon and Washington and found that caregivers believed that ALS patients interested in DWD more frequently experienced insomnia, pain, severe discomfort, and greater distress at being a burden to others in comparison to those who did not discuss wanting DWD. Hopelessness in ALS patients was a major predictor of DWD interest, according to the proxy respondents. Investigators concluded that hopelessness should be addressed as a potential psychiatric or emotional health-related condition affecting DWD decision-making capacity.

In another study of patients with ALS and their caregivers, the majority of caregivers had similar attitudes toward DWD as their patients with ALS did. However, in seven instances, the caregiver believed the patient would not consider DWD as an option when the patient did, and in 14 instances, the caregiver thought the patient would be interested in DWD when the patient was not [25].

Focus group results

Focus group participants were asked a series of open-ended questions about DWD (see [Appendix A](#)).

Public discussion about the DWD Act

The majority of participants had never been asked for their opinions about DWD, although a few had been asked for their opinions during the initial consideration of DWD legislation in the early 1990s. Two participants had been asked about their views on DWD more recently.

According to the focus group participants, the DWD Act did not receive a significant amount of public consideration by the Oregon disability community prior to passage. One participant said, "I don't remember if other disability orgs took a stand. I remember reading something from the Hemlock Society that was really pushing it. I didn't hear a [disability] advocate's perspective at that time." Many of the focus group members described how disability organizations were publicly neutral or distanced in terms of expressing opinions on DWD. "CILS were not taking an active role because it was so controversial," said one participant, "A lot of advocacy groups were afraid to touch it," although another participant added that CILs were silent because they wanted to represent all viewpoints. "My experience was through the [disability] organization I was affiliated with, which addresses issues of lifelong disability," said another participant, who then explained that the organization opposed the legislation privately but that it did not take a public position.

Two participants who had supported the original legislation described their adverse reaction to national groups coming in to Oregon. One group member stated, "There was a national organization—Not Dead Yet—that was absolutely fanatical and put out stuff that was almost incoherent. You couldn't have a conversation with them about it. They were afraid it would be euthanasia. Anytime there was someone from that group, it just shut discussion down. Some of the [local] disability community then came out and said that wasn't their viewpoint. Some of them actually ended up being pro because Not Dead Yet was so anti." Another participant said, "I was offended when the political powers that be at the national level were sticking their oar in and trying to undo what Oregon had done." A different participant said "I was offended a little bit when the media was saying everybody with a disability was in opposition. I thought 'I support it, so some other people probably do too.'" Another group member emphasized the importance of choice in the political debate, "It was seen more as a civil rights issue, a person's right to choose."

Other participants reported that they had limited participation in discussions about the DWD Act. "I was a little out of the loop," said one participant. "It wasn't discussed at all in my town," said another. Others reported that they had heard more from (able-bodied) people who supported

the legislation and that it wasn't until after passage of the DWD Act "that I started to understand the con perspective." One participant stated, "I'm not sure people thought about it as an issue for people with disabilities initially. It became a disability issue over time."

Current opinions

The focus group participants expressed a broad range of views on DWD and believed that there was a similar variety of opinion within the Oregon disability community, including persons in favor, in opposition, and whose positions have changed over time. Roughly one-third of the participants supported DWD and many framed it as a rights issue. "I'm in support of it. I think everyone has the right to make the choice," said one participant. Another said, "I'm still in support ... absolutely." "My view is consistently yes. I want that option for myself," said another participant, "It's ultimately your choice and no one else's." Several participants also framed their support for DWD within the context of what may happen if it is not available. One participant explained, "My father had the same disease I do. There was no DWD, and he was so uncomfortable that he blew his brains out. I've had numerous family members in similar situations who have 'offed' themselves and it's not pretty." Another said, "I've had friends who didn't have the opportunity and they've blown their brains out or starved themselves instead." For these participants, the issue of choice and the potential of more violent suicides justified their support for DWD.

Another group of participants consistently opposed DWD. One participant said, "I've never been in support of it, and I remain not in support." For these participants, the fear of abuse and of health care providers was particularly strong. One participant explained health care providers could not be trusted since a doctor "encouraged me to have my tubes tied instead of reproducing" and doctors have the authority to write DWD prescriptions. For others, DWD was inconsistent with a physician's healing role: "I don't think that's a line we should ask doctors to cross."

A significant portion of the participants had seen their opinions regarding DWD change over time, usually moving from supporting DWD to opposing it. One participant explained, "As I went to college and expanded my horizons, I thought that's a great option if you get sick, like cancer or terminal illness. Now that I live here and know more people with disabilities and terminal illness, I'm opposed to it." Another explained, "I was for it in the beginning and changed my opinion. I had only had a disability about 4 years and wanted the option for myself." A third participant said, "I was completely in support at the time, maybe myopically. I wanted that choice for me. But ... my opinion has swung in the other direction." A different participant said, "I thought initially DWD made sense, but now I think as long as health care is rationed, it's dangerous."

Participants shared several reasons for their shift in opinions including concerns about very limited health treatment

choices for people with disabilities and economic pressures to use DWD. For example, one respondent explained, "After doing a little more research into it, I'm cautious. I want[ed] it for me, but I don't think all options are looked at. If people don't have options, that's not a choice." The respondent was concerned that people with disabilities wouldn't be given options for palliative care or hospice but that their options would be limited to DWD. Another respondent was concerned about the Oregon Medicaid program (the Oregon Health Plan or OHP) providing prescription coverage for ending life but not for life sustaining treatments. She said, "Under OHP, if you want a treatment that will extend your life, OHP won't cover it if you have a terminal diagnosis, but they will give you DWD."

Several participants were concerned that determining that someone is in the terminal stage is difficult. One participant said, "My uncle was given 6 months to live, but he lived much longer and had a good quality of life. I don't think doctors can necessarily say [when someone has 6 months to live]." Another participant described a friend who was given 3 months to live, but ended up living for 5 more years. A third participant said, "I worked in the healthcare field and saw that doctors don't always make the best decisions." Even a DWD supporter said, "I do have sympathy for the situation where you can't get any care but palliative because doctors don't think you warrant it."

Other participants were simply unable to declare support or opposition to DWD. "I don't think it's an easy yes or no," explained one participant. "If it came up for vote again, for me it would depend on the way the law is written. While I agree with everyone who is against it for the reasons they're against it, I don't think we should deny people that option because of...moral views about suicide." Another participant stated, "I've looked at it from both ways and it's very difficult, especially when you're in the disability arena and advocating for people with disabilities." For some participants, the experiences, concerns, and arguments created an unresolved uncertainty about DWD.

Choice and DWD

There was significant discussion on the choice to die. Choice seemed to have several dimensions, ranging from "forced choice" to "empowered choice." Wanting chemotherapy, but only being offered palliative care or DWD was considered a forced choice because "this is a case where some people can get chemo but some can't based on what a doctor thinks. That choice is taken away from those people." Being made to feel that a disability was such a family burden that DWD was an attractive option was also considered a forced choice, particularly in the context of limited information about other options.

Some participants thought that even when one tried to exercise choice, there could be a potential for abuse and neglecting the individual's true wishes. One participant stated, "My fundamental belief is that we should have the right to choose. If we always have the choice, that's

fine, but there are so many situations where that's not the case that I think it can be abused. When a doctor can say someone will have a terrible quality of life and their family can say they wouldn't want to live that way... I know that's not a DWD issue, but it seems like there are enough possibilities for abuse." Another participant echoed this: "I think it's great to have a choice, but it is a slippery slope."

Besides personal issues, the discussion also focused on environmental issues that might affect an individual's choice in terms of end-of-life considerations. Significant attention was given to the areas of health, economic, and social supports needed for people with severe disabling conditions. One participant put it this way, "What's my support system going to be like? Who's going to pay for it? We don't all have the same life circumstances. I read about a woman who could only move her little toe, but had wonderful supports and a good life. That's not necessarily the case for everyone. They might want to go if they don't have those options." Another participant discussed the potential disparity between who receives or does not receive adequate healthcare, "If we start making economic choices about healthcare, at what point does it become only the young, fit, and healthy get healthcare?"

Periodically, group members discussed the importance of empowered choice to guide their personal decision-making. One participant stated, "I want an abundance of education and medical and social supports, and then I think people could make an informed decision without feeling like they are a burden. I agree with others that it's a slippery slope and the door is already too far open in my opinion. I agree we should have empowerment and choice, but there needs to be a foundation for real choices." Another participant shared an example of empowered choice, "Two people I know chose to stop dialysis to end their lives. One of them wanted a sense of permission. His family was there with him. He planned it. They made their choice without the need to go through the DWD hoops." Another participant shared a different empowered choice perspective: "I moved to Oregon in part because of DWD. There are many points I could make, but it comes down to the individual choice and being able to make that choice when the time comes."

Negative consequences

Given the concerns about DWD that emerged when participants were asked about their support or opposition to DWD, the participants were asked directly if they were concerned that DWD could be used against their will. This segment of the focus group elicited many emotion-laden comments. Some participants expressed fear at the possible misuse of the DWD Act. One member stated, "I ... worry about people with borderline functioning who are their own guardians but might be easily influenced." Another participant had reconsidered their organ donor status and said, "I read about the law being able to be used for euthanasia, and I stopped being an organ donor because I thought they

would want to harvest me." A different participant was concerned about the message it sent when health care staff repeatedly asked a spouse about establishing Do Not Resuscitate (DNR) orders: "Those kinds of things opened the door in my mind. Are we really going to take choices for quality care away from people?"

Several members commented on being made to feel a financial burden. "I do think there is a risk of caregivers, doctors, family members viewing you as a financial burden, and people have that guilt," said one participant. A different participant said, "Sometime down the road, I might rely on caregivers a lot more and might be more easily influenced. It's a delicate thing when you rely on other people for your quality of life." Another participant described possible pressure to use DWD: "When I was young and not expected to live past 17, and was made to feel such a burden on my family, yeah I might have taken that choice." One participant described a friend who had survived her terminal diagnosis by 5 years, but had bankrupted her family because of health care costs. "She wondered sometimes whether she should just end it to avoid being a burden on her family," the participant stated.

Other participants were less sure that the DWD program would be misused. One participant argued that since most people who get the prescription don't actually use it, the fear that DWD will be overused is not supported by the statistics. This participant said, "If you think a doctor is leading you down the wrong path, get a different opinion," adding, "Most doctors won't get involved if they can't be sure you have 6 months or less [and] if you're offered DWD, that doesn't mean you have to take it."

Participants also addressed the possible misuse of the DWD protocols. One participant said, "I think that *everyone* who requests it should have to talk to a psychologist to be able to process their decision" instead of leaving it to the discretion of the attending and consulting physicians. Another participant worried that if the drug was not taken properly or it didn't work, "someone could end up more disabled or in agony than they were before." One member cited the importance of taking personal responsibility for understanding the DWD process, "You have to educate yourself to a certain extent. I have an advance directive that's very specific and a primary care physician and friends who support my decision, so I think I wouldn't ever be in a situation where it would be a problem."

"What we should be asking," said one participant, "is whether the protocols in place provide adequate safeguards." Several participants thought the current safeguards were sufficient. The way the law is written, argued one participant, no single caregiver could force its use because "you have to have three doctor's opinions and a bunch of people."

Many of the participants were unfamiliar with the requirement that the DWD medication be self-administered and several expressed concern that this was discriminatory against people with disabilities who were unable to self-

administer the medication. “What if someone gets the drug,” wondered one participant, “but then their functioning reduces and they can’t take it anymore?” “What about someone with ALS?” a different participant asked, “It’s basically forcing them to do it sooner than later before they lose the ability.” Others thought this was a separate issue from misuse of the DWD program. A participant argued, “I agree that they have the right to assistance to do that, but that’s a different question than whether or not there are safeguards to keep me from being whacked against my will.”

Health provider attitudes

Opinions about health care provider attitudes generated the most emotional responses, many of them negative. For example, three separate participants stated:

- “I do believe doctors will think, well you have a disability anyway, you might as well go ahead and end it.”
- “I think you’re more likely to get negative attitude from old-school type of doctors.”
- “It gives a whole lot of power and authority to the medical model. People see physicians as having god-like authority.”

One participant with a physical disability described a personal experience of health care providers’ negative attitudes, “I have sleep apnea and doctors keep telling me to get a [tracheotomy]. They would never tell an able-bodied person that.” Another participant reflected on the past and said, “Historically, people with disabilities are the first ones to go in society. We’re devalued. At the beginning of the holocaust, it was people with disabilities who were killed. It just opens the door a little bit and we all need to be cautious.”

Other participants discussed positive experiences with certain health care providers’ attitudes toward people with disabilities. One participant said, “I saw a nurse practitioner for years because it was more of a collaborative partnership instead of doctors being more hierarchical.” Another said, “I seek out younger physicians because they’re more in tune with patients and more willing to listen to a person with a disability.” One participant was hopeful about changes in the medical education system and said, “I personally don’t see a gender difference, but age and paradigm of health care and disability make a big difference. There has been a lot of education among physicians that disability does not equal death or poor quality of life.”

Perceptions of quality of life

The DWD Act requires physicians who write a prescription for lethal medications to report to OPHD why a patient asked for a prescription for lethal medication. The most frequently cited concerns are: loss of autonomy, decreasing

ability to participate in activities that made life enjoyable, and loss of dignity [14].

The participants were asked if they believed that people with disabilities thought the same about these concerns as people without disabilities. Many of the participants had very strong reactions to this question. One participant said sarcastically, “It’s time for me to jump. I can’t drive anymore; I can’t ride a bike anymore. It’s time to end it. I’ve been blind 25 years. You just have to get over it.” A participant stated, “When I saw *Million Dollar Baby*, I was outraged because it supported the view that she was better off dead even though for the first time in her life she had someone who loved her.”

Most of the participants rejected pain as a basis for DWD. One participant explained, “The pain is nothing. I’m on pain medication.” Another said, “I’ll be another person saying that pain is not the issue.” One participant disagreed, “I know there are issues with pain management. If that were better, people could live longer and better.”

Eventually, a significant dichotomy emerged in perspectives between individuals with congenital and acquired disabilities. As one participant explained, “some people have experienced some of these things from birth. The person who acquires a disability later is going to perceive things very differently... .” However, one participant with an acquired disability said, “I think if people had better supports... . If that were better, people could live longer and better.”

Several participants with acquired disabilities resonated with function and autonomy issues as the basis for DWD. As one participant said, “The loss of function and embarrassment of needing help to use the toilet, it’s humiliating. Pain can be controlled, but loss of functioning and autonomy cannot.” Another said, “It’s really the loss of autonomy.” Another participant was concerned about “deterioration over time.” Conversely, a participant with a life-long disability said, “I was very disturbed by the three top reasons people choose DWD. I’ve never gone to the bathroom myself, so that’s never been a dignity issue for me. It indicates to me what a huge amount of work we have to do to reduce social stigma and views about what leads to quality of life.”

Use of DWD

None of the focus group participants knew Oregonians with disabilities that had used DWD, although one participant knew of two persons who stopped dialysis to cease life function. Several of the participants knew people with disabilities from other states who had taken their lives.

Social validation

Focus groups are dependent on meaningful contributions given and received from group members. Respect for each other’s opinions was very evident in this focus group, with participants displaying a validation of divergent views. One

participant shared, “I respect the opinion of everyone in this room. Everyone has a disability and their own life experience. Maybe I don’t agree with it, but everyone has a valid opinion.” Another said, “I appreciate hearing all different viewpoints. It’s given me more to think about than what you see in the media.” Other participants described their need to maintain public neutrality in their leadership roles within in the disability community, despite their personal opinions about DWD. Several participants made observations about how the topic of DWD needs further reflection and possible action. One participant made the point, “It’s good to have the chance to discuss it, and I feel like I have a lot more research to do.” Another participant expressed the importance of people with disabilities contributing to ongoing discussions concerning end-of-life policies, noting, “Who better to inform these laws than people with disabilities? If we don’t throw ourselves into the dialogue, someone will make these decisions for us.”

Discussion

Review of the empirical literature on DWD in Oregon reveals a number of potential concerns, including inadequate demographic profiling of DWD requesting patients with regard to disability, inadequate mental health evaluations, insufficient duration of physician-patient relationships, potential inaccuracy of the 6-month prognosis, and inadequate exploration of alternative treatment. Of greater concern is the lack of oversight of potential abuses of DWD. The DWD Act creates criminal liabilities for such acts as forging a request for DWD or exerting undue influence or coercing someone to request DWD [1] but does not designate an agency to investigate potential abuses.

Although individuals diagnosed with a progressive disability (ALS) have consistently and disproportionately utilized the DWD program, neither OPHD data nor the empirical literature satisfactorily explores the impact of DWD on people with disabilities more generally. Among focus group participants, DWD remains a challenging and controversial topic with both supporters and detractors. Since preexisting disability is not specifically requested by OPHD compliance forms, physicians do not account for it in the passive surveillance process. More disability identifiers are collected by the DWD advocacy organization Compassion and Choices of Oregon (which has “guided more than 1400 terminally ill Oregonians through Oregon’s aid-in-dying process” [35]) than by OPHD. The addition of preexisting disability identifiers in OPHD data collection would create a mechanism to track DWD usage among different disability populations and facilitate OPHD achieving its mandate “for providing the public with accurate information about the impact of the DWD Act” [4]. In addition, it would assist OPHD in returning to the practice of conducting population-based research on DWD.

The issue of whether DWD disproportionately affects people with disabilities is still unresolved. Battin et al.’s [29] interpretation that people with physical disabilities or chronic illnesses are not at increased risk for DWD does not seem to be supportable given available data. While Tolle et al. [33] used death certificate data to obtain cause of death, this data source does not include disability identifiers; furthermore, reported data from family informants did not yield descriptions of preexisting disability either. Battin et al.’s use of OPHD data should have revealed that patients with ALS, a progressive disability, are significantly more inclined to use DWD. Unfortunately, OPHD does not collect information on disability other than those that are typically acquired later in life and are progressively fatal. It would be unlikely for a physician to cite disability as a terminal illness in the DWD reporting, unless the disability is eventually terminal (such as ALS or MS).

Battin et al. [29] also claimed that no increased risk of DWD was evidenced for patients with psychiatric illnesses. However, data limitations are an issue in this case as well, given that fewer than 10% of DWD participants have received psychological evaluations. DWD patient-physician relationships documented in 2008 included durations that lasted less than 1 week. In addition to adequately informing their patients of the alternatives available to them, physicians are expected to evaluate patient decision-making capacity (without a requirement for psychiatric expertise or psychological consultation) and assess voluntariness of request (without meeting family, caregivers, or other social supports that may or may not influence or coerce the DWD decision) [1]. Accomplishing these safeguards may not be feasible in the course of 2 weeks (standard time period between initial and secondary DWD request), much less 1 week, particularly for physicians unfamiliar with disability and the social and psychological stresses involved. Moreover, the mere presence of an attending and consulting physician system is not empirical proof that this approach ensures competency among requestors of DWD.

It is possible that biased assessments of life with disability may shape physicians’ prognostication for certain activity limiting conditions or influence physicians’ judgment on providing life-sustaining treatment options. For example, the tenth Annual OPHD report indicates that, from 1998 to 2007, the number of days between the writing of the lethal prescription and actual death range from 0 to 698, with median of 7 days [36]. Given that lethal prescriptions are meant for only those with a life expectancy of 6 months or less (roughly 180 days or less), it may be worthwhile to explore what empirical evidence influences prognostications given by physicians. In addition, the focus group repeatedly shared their experiences with disability-based discrimination. Discussions of such public devaluation included encounters with the medical profession. Examples among the focus group participants included health professionals’ proposals for sterilization of one participant, insistence on establishing DNR orders for

a spouse with a physical disability, and suggestions for extreme or radical treatment (i.e., a tracheotomy for sleep apnea) for a wheelchair user. Many of the members of the focus group had themselves challenged this type of social devaluation.

Oregon physicians reported that patients for whom substantive interventions were made (i.e., treatment of depression, provision of social-work services to family, palliative-care consultation) were more likely to change their minds about wanting a lethal prescription. Although economic and time constraints may pose barriers, alternative options for people with disabilities should include efforts to alter demoralizing life situations such as providing dignified in-home personal assistance services [37]. A member of the focus group thought that it would be beneficial for *everyone* requesting DWD to receive a psychological consultation from a health professional, preferably a psychiatrist or psychologist, other than the attending physician. However, mental health assessments performed on individuals with disabilities should be conducted by a health professional familiar with the disability experience. Volicer and Ganzini [38] demonstrated that physicians do not use uniform standards when assessing decision-making capacity among patients with Alzheimer's disease. It is unknown whether these discrepancies affect capacity assessments of individuals with other disabilities. Hopelessness was claimed to disproportionately affect patients with ALS requesting DWD. There is concern that hopelessness may reflect misconceptions about the lived experience of people with disabilities.

Several participants discussed personal choices they had made, such as advanced directives, and (in the case of one participant) moving to Oregon specifically because of the availability of DWD. Some participants revealed that friends and family members had used other means to control the circumstances of their deaths when DWD was not an option. However, participants who publicly advocate for the disability community in Oregon admitted that their personal feelings and public statements regarding DWD legislation did not necessarily overlap. Similarly, participants stated that many disability organizations have not taken a public stand on the issue because it is controversial, and because they want to represent all of their constituents with views across the spectrum of opinions.

Many members of the focus group were concerned about the potential of a "slippery slope" facilitated by the DWD Act. Members expressed concern for individuals who lacked the ability to make an "empowered" and "informed" choice—namely, individuals with disabilities with relatively less economic and social support, less education and political involvement, and less health care access. One participant stressed that the foundation to truly make an empowered choice and establish autonomy did not yet exist. Thus, although members of the focus group saw DWD as somewhat of a personal rights issue, they expressed concern that the historical oppression of people with disabilities, the frequent

biases in health care providers' attitudes, and the lack of self-determination could result in the misuse of the DWD program and ultimately, contribute to an increased risk of DWD for individuals with disabilities.

Limitations

The study has several limitations. First, the study used general literature review methods and not more rigorous systematic review methods. Second, since the focus group was a purposive sample and was limited to certain disability types, it has limited generalizability. Third, there were insufficient qualitative data to develop a more complex grounded theory [10,11,39,40] of the DWD phenomenon.

Conclusion and recommendations

We recommend that the state add preexisting disability identifiers to the DWD forms and designate the state Protection and Advocacy organization, Disability Rights Oregon, as the investigatory authority for cases of potential abuse of DWD involving people with disabilities. Disability Rights Oregon could investigate to determine if the person with a disability selected the DWD without any coercion or pressure and that the person was able to access all the various alternative treatments and therapies they were entitled to receive. This would help avoid moving toward a default to accept DWD as a final treatment option. This oversight is all the more timely given the current deliberations about health care and insurance. There is increased discussion of rationing medical care among people with disabilities [41] and the potential of using DWD as an alternative to health care must be carefully monitored. We also recommend a full review of the procedures, and criteria for evidence that would justify or confirm the choice of a person with a disability to use the DWD option. As part of an overall revamping of DWD procedures, requiring the consultation of one or two psychologists or psychiatric professionals instead of a consulting physician to make a determination of the appropriateness of DWD should be considered.

As this article has described, there are no easy or definite answers about the appropriateness or acceptability of the Oregon DWD Act. The literature and our focus group studies have shown there are multiple facets to the issue. No study is yet available that fully assesses the impact of DWD among individuals with preexisting disabilities. Among focus group participants, there was not unequivocal support for one viewpoint over another. What is clear is that more attention to disability issues in DWD is needed. Additional research, including population-based surveys of people with a range of disability types and durations, is needed. Further, as focus group participants stated, it is important for people with disabilities to actively participate

in DWD-related debates to ensure that concerns of this substantial population are not overlooked.

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References

- [1] Legislative Counsel Committee. *The Oregon Death with Dignity Act § 127.800*. Oregon Revised Statutes, Volume 3 2007. Available at: https://www.oregonlaws.org/ors_chapters/127.
- [2] Oregon Department of Human Services. *Death with Dignity Act*. 2007. Available at: <http://www.oregon.gov/DHS/ph/pas/ors.shtml>.
- [3] Oregon Department of Human Services. *Death with Dignity Act compliance forms*. 2007. Available at: <http://www.oregon.gov/DHS/ph/pas/pasforms.shtml>.
- [4] Higginson G, Hedberg K. *Regarding Oregon's Death with Dignity Act and Oregon State's public health role*. 1998. Available at: <http://www.oregon.gov/DHS/ph/pas/ohdrole.shtml>.
- [5] Fiedler CR, Rylance BJ, eds. *Journal of Disability policy studies: end-of-life issues and persons with disabilities*. Austin, TX: PRO-ED; 2005.
- [6] Nunberg G. *The language of death. The years of talking dangerously*. New York, NY: Public Affairs; 2009; 233-240.
- [7] Raithatha N. Euphemisms must be avoided. *BMJ*. 1998;316:72.
- [8] Glaser BG, Strauss AL. *The discovery of grounded theory*. Chicago, IL: Aldine; 1967.
- [9] Thorne S. Data analysis in qualitative research. *Evidence-Based Nurs*. 2000;3:68.
- [10] Guba EG, Lincoln YS. *Fourth generation evaluation*. Thousand Oaks, CA: Sage Publications; 1989.
- [11] Lofland J, Snow DA, Anderson L, et al. *analyzing social settings: a guide to qualitative observation and analysis*. 4th ed. Belmont, CA: Wadsworth; 2005.
- [12] Creswell JW. *Research design: qualitative, quantitative, and mixed methods Approaches*. Thousand Oaks, CA: Sage Publications; 2003.
- [13] Wolf MM. Social validity: the case for subjective measurement or how applied behavior analysis is finding its heart. *J Appl Behav Anal*. 1978;11(2):203-214.
- [14] Oregon Department of Human Services. *2008 Annual report on the Oregon Death with Dignity Act, Table 1*. 2009. Available at: <http://www.oregon.gov/DHS/ph/pas/docs/yr11-tbl-1.pdf>.
- [15] Oregon Department of Human Services. *Oregon's Death with Dignity Act: the first year's experience*. 1999. Available at: <http://www.oregon.gov/DHS/ph/pas/docs/year1.pdf>.
- [16] Oregon Department of Human Services. *Eighth annual report on Oregon's Death with Dignity Act*. 2006. Available at: <http://www.oregon.gov/DHS/ph/pas/docs/year8.pdf>.
- [17] Legislative Counsel Committee. *The Oregon Death with Dignity Act § 127.800; 127.860, 127.865 Requirements*. Oregon Revised Statutes, Volume 3, 2007. Available at: https://www.oregonlaws.org/ors_chapters/127.
- [18] Oregon Department of Human Services. *Prescription history: Oregon Death with Dignity Act*. 2008 September 3, 2009. Available at: <http://oregon.gov/DHS/ph/pas/docs/prescriptionhistory.pdf>.
- [19] Oregon Department of Human Services. *Oregon's Death with Dignity Act: the second year's experience*. 2000 September 3, 2009. Available at: <http://oregon.gov/DHS/ph/pas/docs/year2.pdf>.
- [20] Ganzini L, Nelson HD, Schmidt TA, et al. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342(8):557-563.
- [21] Chin AE, Hedberg K, Higginson G, et al. *Oregon's Death with Dignity Act: the first year's experience*. Salem, OR: Department of Human Resources, Oregon Health Division; 1999.
- [22] Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon: the second year. *N Engl J Med*. 2000;342:598-604.
- [23] Ganzini L, Goy ER, Dobscha SK. Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *BMJ*. 2008;337:973-975.
- [24] Coombs Lee B, Werth JL. Observations on the first year of Oregon's Death with Dignity Act. *Psychol Public Policy Law*. 2000;6(2):268-290.
- [25] Ganzini L, Johnston WS, McFarland BH, et al. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med*. 1998;339(14):967-973.
- [26] Berkman CS, Cavallo PF, Chesnut WC, et al. Attitudes toward physician-assisted suicide among persons with multiple sclerosis. *J Palliat Med*. 1999;2(1):51-63.
- [27] Ganzini L, Nelson HD, Lee MA, et al. Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death with Dignity Act. *JAMA*. 2001;285(18):2363-2369.
- [28] Ganzini L, Fenn DS, Lee MA, et al. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry*. 1996;153(11):1469-1475.
- [29] Battin MP, van der Heide A, Ganzini L, et al. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *J Med Ethics*. 2007;33(10):591-597.
- [30] Ganzini L, Harvath TA, Jackson A, et al. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl J Med*. 2002;347(8):582-588.
- [31] Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *J Pain Sympt Manage*. 2002;24(3):312-317.
- [32] Ganzini L, Dobscha SK, Heintz RT, et al. Oregon physicians' perceptions of patients who request assisted suicide and their families. *J Palliat Med*. 2003;6(3):381-390.
- [33] Tolle SW, Tilden VR, Drach LL, et al. Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *J Clin Ethics*. 2004;15(2):111-118.
- [34] Fromme EK, Tilden VP, Drach LL, et al. Increased family reports of pain or distress in dying Oregonians: 1996 to 2002. *J Palliat Med*. 2004;7(3):431-442.
- [35] Compassion and Choices of Oregon. *Compassion and changes of Oregon: the Oregon Law*. 2006. Available at: <http://compassionoforegon.org/index.php?a=law>.
- [36] Oregon Department of Human Services. *Oregon's Death with Dignity Act: 2007*. September 30, 2009. Available at: <http://oregon.gov/DHS/ph/pas/docs/year10.pdf>.
- [37] Gill CJ. Depression in the context of disability and the "right to die." *Theor Med Bioeth*. 2004;25(3):171-198.
- [38] Volicer L, Ganzini L. Health professionals' views on standards for decision-making capacity regarding refusal of medical treatment in mild Alzheimer's disease. *J Am Geriatr Soc*. 2003;51(9):1270-1274.
- [39] Patton MQ. *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage Publications; 2002.

- [40] Strauss AL, Corbin JM. *Basics of qualitative research*. Thousand Oaks, CA: Sage Publications; 2007.
- [41] Singer PA. *Why we must ration health care*. 2009; Available at: http://www.nytimes.com/2009/07/19/magazine/19healthcare-t.html?pagewanted=1&_r=1&partner=rss&emc=rss.

Appendix A

Interview Guide

1. Has anyone ever asked your opinion about the Oregon DWD law and its potential consequences or asked the opinion of other people with disabilities that you know?
2. In general, what do you think about the Oregon Death with Dignity law?
3. Some disability organizations have written about their concerns that caregivers, family members, or others might unduly influence decisions about using DWD. Some organizations suggest that using DWD is self-empowerment. How do you feel about these different viewpoints?
 - a. Are you fearful that the DWD law would ever be used against your will? (why or why not?)
 - b. Do you think that the ability to decide when you die is a crucial part of self-determination (why or why not?)
4. The Death with Dignity Act requires physicians who write a prescription for lethal medications under the

Act to report certain types of information, including information about why a patient asked for a prescription for lethal medication. The seven concerns are a concern about:

- the financial cost of treating or prolonging his or her terminal condition;
 - the physical or emotional burden on family, friends, or caregivers;
 - his or her terminal condition representing a steady loss of autonomy;
 - the decreasing ability to participate in activities that made life enjoyable;
 - the loss of control of bodily functions, such as incontinence and vomiting;
 - inadequate pain control at the end of life; and
 - a loss of dignity.
- a. Do you believe that people with disabilities feel the same about these seven concerns as people without disabilities (why or why not)?
5. Do you know of someone with a disability in Oregon that used the Death with Dignity law (to obtain a prescription or end their lives?)?
 - a. If yes, do you know what those experiences were like for the person(s) that used the Oregon law?