

Views of Disabled People Regarding Legalized Assisted Suicide Before and After a Balanced Informational Presentation

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A questionnaire on views regarding legalized assisted suicide was administered to 29 individuals with disabilities (12 participants with various disabilities; 17 participants with multiple sclerosis) before and after their exposure to a “pro” versus “con” informational presentation focusing on disability and assisted suicide. Results indicated that participants who expressed neutrality before the presentation were more likely than participants who had a predetermined position (either opposing or supporting legalization) to change their responses from pretest to posttest. Changes in views, when they occurred, tended toward opposition to legalized assisted suicide. Following the presentations, participants were fairly evenly divided in their endorsement versus opposition to legalized assisted suicide for terminally ill people. Most were opposed, however, to the legalization of assisted suicide for persons with incurable disabilities. Race/ethnicity and gender of participant were important factors, in that women, African Americans, and Latinos were least likely to support assisted suicide. The majority of participants indicated that legalized assisted suicide could lead to involuntary deaths and that safeguards would not prevent abuse. It was concluded that balanced disability-relevant information had a mild effect on attitudes in this study, and that differing levels of knowledge may account for some of the differences in views held by disabled people regarding legalized assisted suicide.

The question of whether to legalize assisted suicide has provoked widespread impassioned debate for almost 2 decades. Although the topic draws considerable media coverage, the information conveyed is rarely comprehensive or representative of diverse voices. Particularly underrepresented has been a disability perspective. Much of the coverage implies that only a narrow group of stakeholders, namely, persons with advanced terminal illnesses, would be affected by legalizing assisted suicide. Yet, leading proponents of assisted dying have included persons with nonterminal disabilities and irreversible chronic health conditions in the category of individuals entitled to legalized assisted suicide.

For example, in his bestselling book, *Final Exit*, Derek Humphry, cofounder of the Hemlock Society, expressed hope for a “more tolerant attitude” toward “justified suicide by a handicapped person” (1991, p. 62). An article in the *New England Journal of Medicine* argued for the inclusion of conditions such as multiple sclerosis in physician-assisted dying (Quill, Cassel, & Meier, 1992). Many proposed statutes for legalizing assisted suicide, such as the frequently cited Harvard Model Act (Baron et al., 1996), explicitly include persons with irreversible but nonterminal conditions. Furthermore, where assisted suicide has been practiced, people with disabilities have

been recipients. Cases linked to Jack Kevorkian, for example, involved nonterminal disabilities such as spinal cord quadriplegia, multiple sclerosis, pain disorders, and chronic fatigue syndrome (Cheyfitz, 1997). In the Netherlands, where physicians have practiced assisted suicide and active euthanasia for years, government reports indicate that persons with both physical and psychiatric disabilities have been helped to die (Hendin, 1997).

The inclusion of people with disabilities as affected parties in the assisted suicide debate raises several critical questions:

- What are the views of people with disabilities regarding legalized assisted suicide?
- If people with disabilities are stakeholders in the matter of legalized assisted suicide, and if that fact is rarely explicitly acknowledged in media coverage or public debate, are they receiving adequate disability-relevant information about the issue?
- How might their views change in response to receiving more information about the topic, focusing explicitly on its relevance for people with disabilities?

Previous Research

Questions of this nature have been inadequately addressed in the research literature. Public opinion surveys on assisted suicide generally do not acknowledge people with disabilities as a distinct demographic group. A notable exception is the Harris Poll on assisted suicide, which has reported results for respondents with disabilities in 1994, 1997, and 2001. According to these surveys, opinions of respondents with disabilities mirror those of the general public, with two thirds endorsing legalized assisted suicide, one third opposing it. Unfortunately, the Harris telephone polls are limited by a number of methodological problems that raise questions about their accurate representation of Americans with disabilities. According to information from Humphrey Taylor, chairman of the Harris Poll (personal communication, July 11, 2002), the survey samples exclude deaf people (because no TTYs [teletypewriters] or telephone relay access were used), individuals in nursing homes or other institutions, persons too poor to have a telephone, people with speech disabilities that limit conversation via telephone, and individuals with physical or cognitive disabilities who generally do not answer the telephone when a surveyor calls because others in their household assume this role for them. Regrettably, such individuals, whose opinions are frequently undocumented, may be among those most affected by changes in assisted suicide policy. Furthermore, the 1994 Harris Poll, which Batavia (1997) and others have cited as primary evidence of the disability community's support of legalized assisted suicide, conflates the responses of individuals with disabilities with the responses of individuals without disabilities who are living with individuals with disabilities. Because this poll lacked a follow-up question to distinguish respondents with disabilities from other members of their households, Taylor has concluded that it is "not correct to report data on people with disabilities from the 1994 poll" (personal communication, July 11, 2002).

In 1999, the disability magazine *New Mobility* published results of a national survey on assisted suicide (Corbet, 1999). Of the responses from 218 people with disabilities, 53% indicated that they would support assisted suicide if satisfactory safeguards were established, while 42% indicated opposition. When asked whether satisfactory safeguards can be established, however, more than half (54%) said no. When asked whether they feared that assisted suicide would be selectively applied to people with disabilities, the majority (64%) said yes. Of respondents supporting assisted suicide, 37% said yes when asked whether they feared criticism from other people with disabilities if they expressed their views. Although all respondents self-identified as disabled, the survey was conducted exclusively through e-mail, thereby excluding many people with disabilities who lack access to online communication (Corbet, 1999).

A recent qualitative study addressed some of the sample problems noted in the previous surveys. Because it is the only published research we could find that systematically documented views toward legalized assisted suicide of people with

various nonterminal disabilities, it will be discussed in detail. Fadem, Minkler, and associates (Fadem, Perry, & Minkler, 2001; Fadem, Blum, Moore, & Rogers, 2002; Fadem et al., 2003; Minkler et al., 2002) conducted in-person interviews with 45 individuals with physical disabilities in the San Francisco, California, area. A Community Advisory Group, composed of six persons with physical disabilities from diverse backgrounds, helped the research team design questions, recruit participants, analyze results, and disseminate findings. According to the researchers, their strategy was to develop not a random or representative sample but one that reflected diversity in terms of disability type (within the category "physical disability"), race/ethnicity, and socioeconomic status. They contacted local disability organizations, particularly those working with people of color, to announce the study and used snowball or word-of-mouth recruitment, encouraging participants to provide names of other people with physical disabilities, particularly those who held different views from their own on the issue of assisted suicide or "death with dignity" laws. The researchers restricted their sample to individuals with physical disabilities expressly because of the pronounced controversy over the issue that has emerged in the community of people with physical disabilities.

Among the major findings, Fadem et al. (2002) reported that 27% of their participants expressed positive views toward death with dignity legislation, 24% were strongly opposed, and 49% were ambivalent. The overwhelming majority of participants reported personal experiences of disability discrimination (87%) that appeared to influence their views on assisted suicide. Themes of self-determination and autonomy emerged in all interview responses. About half (53%) reported that they had experienced, someone they knew had experienced, or they believed they would experience criticism from other people with disabilities if they expressed support of death with dignity legislation, regardless of their actual position. There was no significant association noted between attitudes toward assisted suicide and gender, age, race, class, religion, level of social support, relationship with one's physician, or tendency to self-identify with the disability community. The researchers concluded that despite the strong opposition to legalized assisted suicide expressed publicly by many disability rights groups, there is "a great breadth and diversity of opinion with respect to attitudes toward DWD [death with dignity] or PAS [physician-assisted suicide] legislation" within the disability community (Minkler et al., 2002, p. 18).

It is interesting to note that the 27% of respondents expressing support of assisted suicide in this study is strikingly lower than the 53% in the *New Mobility* survey and the two-thirds proportion in the Harris polls. The lower level of support may be related to the location of the study, near Berkeley, California, an area of thriving disability activism where the probability of exposure to disability-rights information opposing assisted suicide is high. An alternate explanation may reside in the large proportion of responses that were categorized as "ambivalent." The researchers gave examples of sev-

eral responses in this category. However, it appears that some of these examples could be categorized just as reasonably as “supportive” or “opposed.” To illustrate, one of the examples of an “ambivalent” response was, “I do not believe there should be any type of legislation. I also think there should not be legislation against it. It is a very personal decision. Some people are going to come to a point in their life where they want to end it. That is a very personal decision” (Fadem et al., 2002, p. 7).

Although categorized as “ambivalent,” the quoted respondent appears to oppose assisted suicide as public policy and to define the decision to end one’s life as a personal matter that should remain outside the reach of legalization. This position, in fact, echoes the formal positions of disability-rights groups who distinguish between the private act of suicide, which is not illegal, and proposed laws that would decriminalize the involvement of a second person in assisted suicide—a change in law that the groups oppose. In other words, the response is certainly complex but is not necessarily ambivalent regarding the issue of legalizing assisted suicide.

Similarly, another study finding was a “contradiction” between some respondents’ “personal experience and their abstract or political beliefs.” Again, the researchers seemed to perceive a contradiction where others may see a well-developed but complex policy stance transforming “the personal” into “the political.” Arguably, the disability-rights opposition to legalized assisted suicide is a call to place the collective interests of the disability community (including those most vulnerable to medical system abuse) above personal interest in a comfortable guaranteed death. This position is perhaps best articulated in a study response that the researchers characterized as contradictory:

Unless they really go out of their way to learn more about this issue, more than likely they will be pro—you know—pro Death with Dignity, because they would know a lot more people like my grandmother [who suffered a painful cancer death]. And so, if you’re not as politically observant, maybe, if you don’t realize how vulnerable people with disabilities can be to their health providers, you’re going to be influenced by these dramatic stories, you know, and they are very dramatic. (Fadem et al., 2001, p. 6)

Although the researchers said their goal was “to uncover the attitudes of people with disabilities toward DWD/PAS [death with dignity/physician-assisted suicide] legislation” (Minkler et al., 2002, p. 15), their analysis seems to blur respondents’ position on such legislation with personal feelings and other informally stated ideas about dying. In fact, the researchers’ interview guide uses the words *feel* or *feelings* in most of the opinion questions. It seems reasonable that one can experience a range of complicated feelings about a controversial topic—such as capital punishment, abortion, censorship, or even assisted suicide—yet still arrive at a firm policy position. It would be interesting to see whether a re-

analysis of responses in the “ambivalent” category might yield additional responses that are qualitatively complex but nonetheless “supportive” of or “opposed” to assisted suicide as public policy. If so, the percentage of “supportive” and “opposed” responses might shift significantly from currently reported levels.

Another aspect of this study that warrants attention is the researchers’ conclusion that their results demonstrate divergent opinions in the disability community on legalized assisted suicide. The implication is that they uncovered a diversity of opinions that may commonly remain suppressed because of feared criticism from peers. Such conclusions should be tempered by the possibility that sampling strategies may have predetermined the collection of divergent opinions, in that participants were specifically asked to refer other participants “whom they believed might hold views toward DWD or PAS legislation *different from their own*” (Minkler et al., 2002, p. 17, italics added). Furthermore, as the researchers correctly stated in their methods section, qualitative data collected from a nonrandom sample drawn from one geographic area cannot support any conclusions about the disability community in general.

The research reviewed prompts several questions regarding the views of people with disabilities on legalized assisted suicide. How much are past survey findings artifactual, that is, influenced by methodological issues such as sampling bias or exclusion and lack of access to the mechanism of response? If some of the methodological problems could be resolved, what percentage of people with disabilities would actually indicate support versus opposition to the policy of legalized assisted suicide? How much are differences in views attributable to differences in amount or type of exposure to disability-relevant information? Are race and gender significant variables, or does disability “trump” their effect?

Project Goals

The goals of this research project were

1. to present a balanced informational presentation for adults with disabilities regarding disability and assisted suicide, and
2. to assess the effect of the informational presentation on participants’ views of assisted suicide via questionnaires administered before and after the presentation.

In view of limitations in past research, we endeavored to design a pilot study that would

1. provide an accessible and confidential instrument to elicit the views of people with disabilities on disability-relevant aspects of assisted suicide policy;
2. recruit a cross section of the disability community to participate, including persons with physi-

- cal, communication, sensory, or psychiatric disabilities; those living in group/supported living settings; and those needing transportation and personal assistance to participate;
3. recruit a particular subsample of individuals with multiple sclerosis, a condition that has been linked to assisted suicide practice in the United States and in the Netherlands; and
 4. prioritize diversity of participants according to gender and race/ethnicity.

To make the communications, content, and instruments of this project as unbiased as possible, we consulted two organizations known for strong advocacy on either side of the issue: the Hemlock Society (a group that promotes legislation to legalize physician-assisted suicide) and Not Dead Yet (a disability-rights group opposed to legalized assisted suicide). We worked with representatives of these organizations to develop the research materials and procedures.

Method

Sample

The participants were 29 adults with disabilities living in the Chicago area, recruited through two local disability organizations: a center for independent living and a branch office of the Multiple Sclerosis Society. To protect the confidentiality of their “customers,” the staff of those organizations distributed the project announcement widely to individuals associated

with their centers (including persons in institutions and group settings), directing interested volunteers to contact the research team for additional information. When volunteers made contact, they were given information about the research presentation and its purpose, the nature of the questionnaires they would complete, their rights to confidentiality and to withdraw from participation, and the amount of payment (\$50) for participation. The team also conveyed details regarding the time and location of the event and checked on needed disability accommodations, such as paid transportation, alternate communication formats, or assistance with writing.

Because we were interested in the relationship between views on legalized assisted suicide and several participant characteristics, including disability type, participants were classified into two groups: the Cross-Disability group, composed of individuals recruited through the center for independent living, and the MS group, composed of individuals recruited through the Multiple Sclerosis Society. Demographic data on the participants are summarized in Table 1.

Presentations

The informational session was 1.5 hours long, consisting of a 30-minute presentation by two speakers endorsing the legalization of assisted suicide (referred by the Illinois Hemlock Society), a 30-minute presentation by two speakers opposing legalization (referred by the organization Not Dead Yet), and a 30-minute question-and-answer session involving all the speakers and the audience. The presentation was conducted twice in 1 day—to the Cross-Disability group in the morning and then to the MS group in the afternoon. The presentations

TABLE 1
Sample Characteristics of Research Presentation Participants

Group	n	Age (yrs.)	Gender	Race/ethnicity
Total sample	29	23–71 M = 47.8	20 women 9 men	13 White 11 African American 2 Latino 2 multiracial 1 not stated
Cross-disability group ^a	12	23–57 M = 44.3	7 women 5 men	6 White 3 African American 1 Latino 2 multiracial
MS group ^b	17	39–71 M = 50.5	13 women 4 men	7 White 8 African American 1 Latino 1 not stated

^aNine of the 12 participants in the Cross-Disability group reported having physical disabilities exclusively, 1 had both a physical disability and blindness, 1 had both a physical disability and a psychiatric disability, and 1 had a psychiatric disability exclusively. The physical disabilities listed by Cross-Disability group participants included spinal cord injury, post polio, osteogenesis imperfecta, arthritis, and neurological disorders (including 1 person with multiple sclerosis). ^bAll participants in the MS group reported multiple sclerosis as their exclusive condition.

were virtually identical except that the order of speaker teams (pro vs. con) was reversed to counterbalance any rhetorical advantage associated with speaking first or last.

Both speaker teams were instructed to develop factual and persuasive presentations of their positions on the issue of legalized assisted suicide, paying particular attention to the interests of people with disabilities. Aside from the strictly imposed time limits, teams had latitude to structure their presentations as they wished. Each team consisted of one man and one woman. In each team, the woman had a visible physical disability and the man had no visible disability. The teams conveyed information on the history and current status of assisted suicide practices and policies, described their organization's efforts, presented points supporting their positions, and addressed issues relevant to disability. Each presentation was in lecture format with the use of overheads. Before leaving, participants received a packet of materials from both speaker teams to take with them. The packet included readings, fact sheets, summaries of proposed laws, interpretations of the laws, and contact information for organizations concerned with the issue.

Questionnaires

Questionnaire items were developed by the project team after reviewing existing materials on assisted suicide and disability (articles in journals and books, articles in the disability press, newspaper stories, press releases, etc.) and were approved by the presenters (questionnaire items are presented in Table 2). Items focused on attitudes toward legalized assisted suicide, perceived consequences of legalization, and stakeholder involvement. Two knowledge questions were also included to determine participants' grasp of the distinction between legalized assisted suicide and both private suicide and treatment withdrawal. Questionnaire A, the "pretest" version, presented 10 items about beliefs and attitudes toward assisted suicide, allowing the participant to indicate level of agreement on a 5-point Likert scale. There also were two multiple-choice sentence completion items, an open-ended question asking the participant to briefly state her or his views on assisted suicide, and a brief demographic section.

Following the presentation, each participant completed Questionnaire B, the "posttest" version, containing the same items as the pretest with the addition of a question asking if and how her or his views changed as a result of the presentation. Participants also completed a short evaluation form about the event and the speakers.

Confidentiality and Consent

To allow for response anonymity, each participant blindly selected a confidential identifying code from a container and was instructed to write the number on both questionnaires. A consent form approved by the Institutional Review Board of the project director's university was distributed to all participants

to inform them about the procedures and purposes of the project and the right to withdraw. The project director read the form aloud after distribution, answered participants' questions, and collected the signed forms before the presentations began.

Accessibility

The presentations took place in a well-lit, wheelchair-accessible university auditorium with accessible restrooms within 100 feet. Assistants were provided to help participants as needed. Large-print versions of all materials were available for persons with low vision.

Analysis

Response patterns were analyzed per item by group (Cross-Disability and MS) in terms of percentage of participants indicating agreement (*somewhat agree* or *strongly agree*), disagreement (*somewhat disagree* or *strongly disagree*), and neutrality (*neither agree nor disagree*). Change in responses from pre- to postpresentation was analyzed in relation to gender, race, age, and disability variables (type, duration, stability). A descriptive approach was used to detect theoretically meaningful findings, as the pilot sample sizes precluded significance testing. Open-ended responses were coded and analyzed qualitatively by three members of the research team (all persons with disabilities) for thematic patterns. Evaluation responses were summarized and reviewed for information to guide future revisions of the presentations and materials.

Results

Response patterns are reported in the context of associated questionnaire items.

The Main Questions

The first two items addressed the main issue of whether assisted suicide should be legalized:

Question 1—Physician-assisted suicide should be legalized for mentally competent adults with advanced terminal illnesses.

Question 2—Physician-assisted suicide should be legalized for mentally competent adults with incurable but not terminal disabilities, such as quadriplegia.

On the question of legalization for persons with terminal illness, the two disability groups differed noticeably. In the Cross-Disability group, prepresentation responses indicated that 67% (8/12) favored legalization, 25% (3/12) opposed it, and 8% (1/12) expressed neutrality. Subsequent to the presentation, the breakdown was 58% (7/12) in favor, 42% (5/12) opposed,

TABLE 2
Questionnaire Items

1. Physician-assisted suicide should be legalized for mentally competent adults with advanced terminal illnesses.
2. Physician-assisted suicide should be legalized for mentally competent adults with incurable but not terminal disabilities, such as quadriplegia.
3. If assisted suicide is legalized for those who request it voluntarily, it will ultimately lead to instances in which persons who do not request it are helped to die involuntarily.
4. If doctors were legally permitted to help someone with a disability to commit suicide upon request, they might become less motivated to preserve the lives of other persons with disabilities during medical emergencies.
5. A 34-year-old man has been paralyzed from the neck down since age 26 from an auto accident that occurred 3 weeks before he finished medical school. He lives in a nursing home because he needs assistance for most activities of daily living. After thinking about his life and death options for several months, he decides he no longer wishes to live. The law should permit a person in this situation to obtain a lethal injection from a physician.
6. Legalizing assisted suicide is a way to prevent the kind of activities engaged in by Jack Kevorkian.
7. If assisted suicide becomes legal, even the most carefully written safeguards will fail to protect some people with disabilities from abuse or wrongful death.
8. Suppose a man in Illinois needs a ventilator full time to breathe. He decides his life lacks quality and asks his doctor to sedate him and withdraw the ventilator so he can die. After waiting 2 weeks to make sure her patient is persistent about wanting to die, the doctor follows through on the man's request, and he dies in his sleep. This doctor has violated the law as it stands now.
9. If a person has a disability that is progressing, and that person chooses to die before becoming dependent on others for assistance in daily living, that person should not have the legal option of getting a prescription for a lethal dose of drugs.
10. It is illegal to commit suicide, even if someone does it privately without any help from anyone.
11. Legalizing assisted suicide would give the most power to:
(Doctors, Patients, Family members, No one)
12. Money issues will most likely become a relevant factor in assisted suicide decisions for:
(Doctors, Patients, Family members, No one)

In the space below, please summarize your views as they stand right now on legalized assisted suicide.

and 0% (0/12) neutral. These results suggest that before the presentation, the group's responses were consistent with the "two thirds in favor" figures reported in most public opinion polls on physician-assisted suicide. Subsequent to the presentation, however, the pro-versus-con proportions approached a "fifty-fifty split" (with "pro" and "con" numbers differing by only one respondent), and the direction of change was toward opposition.

In the MS group, the prepresentation breakdown was 41% (7/17) in favor, 47% (8/17) opposed, and 12% (2/17) neutral. The postpresentation breakdown was 47% (8/17) in favor, 47% (8/17) opposed, and 6% (1/17) neutral. In contrast to the Cross-Disability group, the MS group came to the event more evenly split on legalizing assisted suicide for persons with terminal illnesses, and exhibited little change.

On the question of whether assisted suicide should be legalized for persons with incurable but not terminal disabilities, the prepresentation breakdown for the Cross-Disability group was 17% (2/12) in favor, 58% (7/12) opposed, and 25% (3/12) neutral. Subsequent to the presentation, the break-

down was 33% (4/12) in favor, 58% (7/12) opposed, and 8% (1/12) neutral. Slightly over half of these participants came to the event opposing legalization of assisted suicide for people with disabilities—a proportion that remained unchanged following the presentation. The two participants who changed toward favoring legalization for people with disabilities had consistently favored legalization for persons with terminal illness. In a sense, their views favoring assisted suicide became more consistent after the presentation, encompassing nonterminal as well as terminal conditions.

In the MS group, the prepresentation breakdown was 35% (6/17) in favor, 53% (9/17) opposed, and 12% (2/17) neutral. Following the presentation, the breakdown was 29% (5/17) in favor, 65% (11/17) opposed, and 6% (1/17) neutral. Similar to the Cross-Disability group, slightly more than half of the MS group came to the event opposing assisted suicide for people with disabilities. In contrast to the Cross-Disability group, however, the MS group's opposition rose to approximately two thirds following the presentation.

There was an interesting gender difference in these two questions. According to postpresentation responses, the majority of the men favored legalizing assisted suicide for terminally ill people (78%, 7/9), and about half favored legalization for people with disabilities (56%, 5/9). In contrast, only a minority of the women favored legalization for terminally ill people (35%, 7/20) and people with disabilities (20%, 4/20). Furthermore, slightly more than half (55%, 11/20) of the women expressed the most extreme level of disagreement (*strongly disagree*) with legalization for both terminally ill people and individuals with disabilities.

Race/ethnicity also appeared to be an important factor in views of assisted suicide. According to postpresentation responses, the majority of White participants favored legalization of assisted suicide for terminal illness (85%, 11/13), and about half favored legalization in the case of disability (54%, 7/13). The corresponding figures for African Americans and multiracial participants were lower: 31% (4/13) and 15% (2/13). Neither of the two Latino participants favored legalization in the context of either terminal illness or disability. Race/ethnicity also may have factored in how participants changed their position on Question 2 (assisted suicide for people with disabilities) following the presentation. Although the number of participants changing their views on this item is too small to support conclusions, it is interesting to note that in the Cross-Disability group, both participants who changed toward endorsing legalization for people with disabilities were White. In contrast, the other participant in this group who changed position on the item was an African American woman who moved from a neutral position toward opposition. Similarly, in the MS group, two participants, both women, moved toward opposition of assisted suicide for nonterminal people with disabilities. One was African American, and the other did not state her race/ethnicity.

No response patterns related to age could be discerned. Duration of disability also did not appear to be associated with any particular response pattern. However, only four participants in this project had been disabled less than 5 years. The mean duration of disability was 19 years in both the Cross-Disability group and in the MS group. Because multiple sclerosis is often characterized as a progressive disability, it was not clear initially whether the response patterns in the MS group noted earlier were related to this particular disability (multiple sclerosis) or to the confounded factor ("stability"). Therefore, an attempt was made to look at the association between disability stability (across different types of disabilities) and views toward legalizing assisted suicide. The results revealed no systematic relation of disability stability to the questionnaire responses.

Other Questions

The response patterns on other questions were complex and frequently difficult to interpret. The most consistent finding was that persons who felt strongly about an item before the

presentation, regardless of the direction (agree or disagree), were not likely to change considerably in their views. This trend was confirmed by responses to the open-ended questions that asked participants to state their views in their own words. Most participants indicated that the presentation had not changed their views, although several who came to the event opposing assisted suicide reported that the presentation strengthened their opposition. Persons who came to the event expressing neutrality were most likely to change, and the direction of that change was most likely to be toward opposition to assisted suicide or concerns about its consequences.

Several items yielded particularly interesting responses. The majority of participants in both groups believed that legalization of assisted suicide might eventually lead to involuntary deaths (52% or 15/29 prepresentation; 62% or 18/29 postpresentation). The majority also felt that legalization of assisted suicide for people with disabilities might decrease physicians' motivation to preserve the lives of these persons during medical emergencies (62% or 18/29 prepresentation; 69% or 20/29 postpresentation). Similarly, the clear majority of participants agreed that the best safeguards would not protect some people with disabilities from abuse or wrongful death if assisted suicide were legalized (69% or 20/29 prepresentation; 71% or 20/28 postpresentation). The majority opposed a lethal injection for a hypothetical competent adult quadriplegic who expressed an unremitting wish to die (62% or 18/29 prepresentation; 52% or 15/29 postpresentation)—a scenario with parallels to the case that led to the conviction of Jack Kevorkian.

Two knowledge questions were included to gauge how well participants understood the different legal status of treatment withdrawal versus assisted suicide and private suicide versus assisted suicide. The majority of the participants (69%, 20/29) initially believed that the law still prevents doctors from withdrawing a life-supporting ventilator even if a competent patient requests withdrawal. Although a few participants changed their answers in accord with the facts regarding the legality of treatment withdrawal following the presentation, most still responded incorrectly (57%, 16/28). In the same vein, the majority came into the event believing private suicide was illegal (59%, 17/29). However, following the presentation, many respondents changed their answers in accord with the fact that private suicide, as opposed to assisted suicide, is not illegal (32%, 9/28).

When asked who is most likely to gain power if assisted suicide is legalized, most indicated that doctors would gain the most power (43%, 12/28), followed by patients (29%, 8/28), family members (14% 4/28), and no one (14%, 4/28). When asked which party would be most affected by money issues in making assisted suicide decisions, most indicated it would be family members (48%, 13/27), followed by patients (22%, 6/27), doctors (15%, 4/27), and no one (15%, 4/27). Interestingly, despite current controversies over managed care, few participants indicated that money issues might affect doctors. Participants' answers on both of these items remained essentially unchanged from pre- to postpresentation.

Most participants rated the event highly on their evaluation forms. They generally indicated positive reactions to the scheduling and accessibility of the event and to the content and format of the presentations. In rating the quality of the speakers, participants tended to prefer the speakers with whom they agreed on the issue. Several suggested that the time for the presentations and discussion should be longer to allow more in-depth coverage of the topic.

Discussion

The results of this project suggest that a balanced informational presentation on disability and legalized physician-assisted suicide had some effect on the knowledge and attitudes of two groups of people with disabilities. In general, persons who came to the presentation with strong views on the subject changed very little compared to individuals who had initially expressed neutrality. When change occurred between pre- and postpresentation views, the change was more likely toward opposition to the legalization of assisted suicide. This suggests that for individuals with disabilities who have not yet adopted a firm position on the topic, exposure to pro and con information in a disability context may help them to decide. Furthermore, when they move off the fence, they may be more likely to move toward opposition than to support. This is consistent with the low level of support for assisted suicide found among individuals with disabilities in the San Francisco Bay Area (Fadem et al., 2002), who are most likely to have been exposed to disability-rights information, in contrast to the higher levels of support in the Harris polls, which target a population-based national sample.

Although some proponents of legalization have expanded the qualifying conditions for assisted suicide to include incurable disability as well as terminal illness, most individuals with disabilities in this study (62%, 18/29) opposed assisted suicide for people with disabilities. Participants were more evenly split on the issue of legalization for people with terminal illnesses (45%, 13/29, indicating opposition; 52%, 15/29, indicating approval; 3%, 1/29, indicating neutrality).

Persons with MS were more likely to express opposition to assisted suicide than were participants in our Cross-Disability group. This result contradicts expectation. MS is associated with the progressive loss of function that some proponents of assisted suicide cite as a reasonable basis for facilitated dying. Furthermore, a significant number of persons with MS have been portrayed in the media as requesting and receiving assistance to die. Interestingly, when "stability" of disability was examined separately, there was no detectable relation between "progressiveness" of a person's disability and her or his views on assisted suicide. A possible clue to the greater proportion of "opposed" responses in the MS group is that they were older than the Cross-Disability group; however, as in the Minkler et al. (2002) study, there was generally little ev-

idence of a relationship between age and views on assisted suicide for our sample as a whole.

Our results underscore the importance of examining the role of race/ethnicity and gender in mediating views of people with disabilities regarding assisted suicide. Consistent with research on attitudes toward assisted suicide in the general population, women with disabilities were more likely than men to oppose legalization, and persons of color were more likely than White persons to express opposition. African American and Latina women with disabilities were the most likely of all to express opposition. These results validate the conviction of many disability studies scholars that intersecting identities and intragroup variability within the disability community should be recognized when studying the disability experience (Alston, Bell, & Feist-Price, 1996; Vernon, 1998).

The clear majority of our participants believed that legalizing assisted suicide could have dangerous consequences, including involuntary deaths (62%, 18/29), decreased motivation of physicians to preserve the lives of people with disabilities during emergencies (69%, 20/29), and despite safeguards, abuse and wrongful death (71%, 20/28). These results coincide with the *New Mobility* survey in which the majority of respondents said they feared that assisted suicide would be selectively applied to people with disabilities and that satisfactory safeguards could not be established. The majority of our participants opposed active euthanasia for people with disabilities (62%, 18/29). When asked which constituency would gain the most power from legalization, most said it would be physicians, but almost none believed physicians would be influenced by money considerations. Most perceived family members as those most likely to be concerned about money matters in decision making about assisted suicide.

Factual items indicated that a significant number of participants incorrectly believed that it is illegal to withdraw unwanted life-support treatment or to commit suicide on one's own, privately. The presentation was effective in correcting the mistaken beliefs of many participants, but there was evidence of lingering confusion regarding these components in the debate on assisted suicide.

Our study also offers pilot confirmation of the utility of our questionnaire in eliciting views on legalized assisted suicide from people with disabilities. We made an effort to word questions in a manner that did not confound one's personal feelings or conflicts about dying with one's chosen position on legalized assisted suicide as public policy. We also chose to use exclusively the widely adopted term *assisted suicide* rather than the more euphemistic (and, arguably, politically partisan) term *death with dignity*. In addition to the positive feedback we received from participants regarding its clarity and relevance, we noted that the questionnaire yielded results consistent in many ways with past surveys, particularly in terms of pro versus con response patterns and the effects of gender and race. Furthermore, the consistency of responses from pretest to posttest for individuals with strong positions lends support to the validity and reliability of the instrument. The fact that most individu-

als with disabilities can complete the code-identified questionnaire in complete privacy, or with minimal assistance, allowed our participants to express their views on a controversial topic with minimal risk of public exposure and censure.

Study Limitations and Future Directions

The most obvious limitation of this study is the small sample size. Another is the use of only one data collection site. Future efforts to replicate this research should construct a larger sample to allow significance testing of differences between subsamples (women vs. men, different racial/ethnic groups, different disability types) and between prepresentation and postpresentation responses. Data collected from different areas of the country should be compared to ensure that response patterns are not region specific.

Another possible limitation is that we recruited participants only through disability organizations and relied on prospective participants to contact us. As a consequence, our sample may have included a higher-than-average number of individuals exposed to disability advocacy, and some may have self-selected because of high investment in the topic. However, to minimize that bias, we used organizations that serve many “nonactivist” individuals, and our sample included people with disabilities with a broad range of demographic characteristics, backgrounds, and disability types. Future large-scale studies should use multiple recruitment strategies for inclusion of a cross section of the disability community, including a significant proportion of individuals who are not immersed in disability-rights activism or activism on this topic. The variable *activism* and its contribution can be examined more precisely by adding an item to the demographic section of the questionnaire to elicit information about the respondent’s level of involvement in activism.

On the basis of evaluative feedback, another limitation of the study was the brevity of the information session. Fitting both pro and con presentations and a question-and-answer period into the 90-min. slot made the session seem too rushed and superficial for some participants. Extending the time to at least 3 hours and scheduling a discussion after each presentation might allow for a better test of the effect of information on participants’ views. More in-depth coverage of issues might also increase the effectiveness of the presentation in correcting factual inaccuracies in participants’ knowledge of assisted suicide and current legal options.

Conclusion

Our results suggest that differing levels of knowledge of disability-relevant information may account for some of the differences in views held by people with disabilities regarding legalized assisted suicide. A balanced presentation of information on disability and legalized assisted suicide had a mild ef-

fect on the knowledge and views of people with disabilities. The effect was most apparent for individuals who approached the training without a strong position either in support or opposition. The direction of change following exposure to the information tended to be toward opposition. Given the small number of participants in this project, it is recommended that attempts to replicate this study include more participants in various settings, use multiple sample recruitment strategies, examine the contribution of activism, and use longer, more comprehensive presentations. Subsequent research should continue to examine the importance of often-overlooked participant variables, such as race/ethnicity, gender, age, and class. This project suggests that some of the within-group variability that has been found in the views of people with disabilities on assisted suicide may be related to the values, experiences, and resources of different segments of the disability community and to their access to information relevant to their experience.

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