

Reflections on the debate on disability and aid in dying

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Abstract

Background: A policy resolution supporting physician aid in dying was proposed to the American Public Health Association (APHA) in 2007 that prompted a debate with the Disability Section on its meaning for people with disabilities.

Objective: The present paper reflects on the issues revealed and lessons learned.

Methods: The debate included subcommittee discussion; review of research, polls, administrative reports; discussion with disability rights organizations; and floor-debate and vote by the APHA Governing Council.

Results: Reflections on the process are summarized under the themes: we all have our own views; it's highly personal; confusion among key concepts; I might want it for myself; it's about control and not about pain; the slippery slope and other arguments; and undue burden on people with disabilities.

Conclusions: The APHA resolution supporting aid in dying was passed in 2008 with some improvements in the language and a recommendation to measure pre-existing disability. Valuable lessons were learned through the debate process. Published by Elsevier Inc.

Keywords: Disability; aid in dying; physician-assisted suicide; policy

Background

In the summer of 2007, the Disability Section of the American Public Health Association (APHA) was thrust into a fierce debate on physician-assisted dying and its implications for people with disabilities. Over the next 15 months, this issue would dominate the energy and activity of the executive committee members tasked to work on it. A policy resolution had been proposed before APHA's Governing Council to support in principle state legislation allowing physician-assisted dying for terminally ill adults. The policy resolution was based on Oregon's legislation on physician-assisted dying. In 1994, Oregon passed the "Death with Dignity Act," the first legislation in the United States that would allow some terminally ill adults to voluntarily end their lives through the self-administration of lethal medications received through prescriptions from physicians. A subsequent measure in 1997 sought to repeal the act but

was rejected by voters, and the Death with Dignity Act was enacted in the fall of 1997. It included a number of safeguards but not a measure of preexisting disability status and required that the Oregon Health Services Division provide annual reports on the implementation of the Act. This paper summarizes reflections on the lessons learned through the process of the APHA debate.

Methods—The process of the debate

The APHA policy resolution on physician-assisted dying had come to the attention of the Disability Section (then Special Interest Group) executive committee in early summer of 2007 and was scheduled for a vote by the Governing Council of APHA at the fall 2007 APHA meeting. The Disability Section rapidly organized to examine the proposed policy and then to oppose its passage in 2007, arguing for a more complete review of the issues before a vote was taken. With support from several other councilors and APHA executive members, this initial opposition was successful in delaying the vote. Given the level of organized support for rapid passage of the resolution, this delay was celebrated as David successfully warding off Goliath in APHA policy development. However, this was only a delay of the vote and required that the subsequent 12 months be spent in examining the disability community concerns more

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closely, reaching out to other APHA Sections, and attempting to negotiate a compromise with the sponsor of the resolution prior to a vote in fall of 2008.

Suzanne McDermott, the policy chair of the Disability Section, led a small subcommittee in reviewing the issues and later opposing the resolution. I served as chair of the Disability Section through the fall of 2007, and then as a member of the Disability Section subcommittee that worked on testimony and strategy on the resolution. With Suzanne and several others, I read scores of research studies on physician-assisted aid in dying and related issues, examined national polling surveys on the issue, and reviewed numerous policy analyses, and analyzed each of the annual reports filed by the Oregon Department of Human Services on the Oregon Death with Dignity Act. The subcommittee held regular telephone calls and talked with representatives from national disability organizations. The process was emotionally taxing for all who got involved, demanding that we examine and discuss our own fears and conceptions of death, disability, and control, and navigate through the different and strongly held views. During the times of most intense work, members of the subcommittee acknowledged experiencing sleep disturbance and intrusive thoughts, and the issue dominated all discussion of the Disability Section executive committee for months.

Results—Lessons learned

The APHA debate on physician-assisted dying was not a debate that any of the Disability Section executive members wished for but, in retrospect, the experience taught us a great deal.

We all have our own views

Polling surveys repeatedly document that the American public is highly divided on the right to physician-assisted dying. Opinion polls on the issue report roughly equivalent numbers of supporters as opponents, with wording of the survey question being critical in determining in which direction the majority opinion will fall [1,2]. Opinion of the organized disability community was united in opposition [3], but individual opinions of persons with disabilities were more mixed and similar to the general population (see Drum et al. [4] in this volume).

Living in Oregon during the years that the Death with Dignity Act was passed and implemented, I witnessed the highly passionate and volatile debates on the bill. Disability advocates were not highly visible in the Oregon debate, and active public opposition came primarily through religious organizations arguing for the sanctity of life. For some opponents, the Oregon Death with Dignity act was seen as “pure evil.” But for other Oregonians, it was regarded as a humanitarian policy in line with other socially progressive policies of the State. After all, wasn’t Oregon the first

state in the country to enact a bottle recycling bill in 1971, and a pioneer in reforming public funding of health care to achieve near universal coverage in the early 1990s?

I also had more personal involvement with dying. In the spring of 1996, my father-in-law was diagnosed with terminal cancer. He was a man whom I loved deeply, and I flew to Illinois to support my mother-in-law in providing home respite care during the last weeks of his life. He struggled with nearly continuous pain and I should have recognized, but didn’t, that he was likely undermedicated for most of those last weeks. During a period of lucidity, he let us know he wasn’t ready to die yet and lived for another week before passing away quietly. Participating in his dying had a profound impact on me, and more than a decade later, I understood with greater compassion the accounts of families’ wanting to respect their family member’s wish to die a more rapid death [5].

Some members of the APHA Disability Section committee regarded the policy as reprehensible on moral grounds, while others opposed it because of its threat to disability rights. Because of my personal experiences of living with the Oregon Act for a decade and recognizing its potential value, I was more ambivalent on the issue and had stepped back from a leadership role, offering instead to review relevant research.

It’s highly personal

The formal guidelines on development of APHA policy indicate that policies should be based on scientific evidence. Objectivity of science, however, readily slipped away. The language of the original resolution relied on argument and persuasion, and only presented science that supported the resolution. The Disability Section experienced a similar phenomenon. Despite an early recommendation that the group set aside personal feelings on the topic and focus on the implications for disabilities, one member noted, “How can you?—It’s all too personal.” The issue rapidly became polarized.

When the Disability Section executive committee solicited section members’ views, their responses reflected an array of personal opinions. One health care provider advocated that support for the resolution be framed in extremely clear language to protect any health care professionals who might implement the policy; another member opposed it on the presumption that it was specifically directed toward ending the lives of people like her aunt who have disabilities. Passionate personal advocacy was not exclusive to the disability community. When members of our committee met with the Oregon Public Health Association (OPHA) leadership, one OPHA member became highly impassioned, arguing that right to assisted dying should not be “held hostage by the disadvantaged few.” He described a family member who had recently become quadriplegic as a result of a motor vehicle collision, and questioned whether life with such a severe disability was worth living. The essence of his argument was that significant disability

should entitle a person to the right to end their life. This interpretation went far beyond the Oregon law and the proposed resolution.

Confusion among key concepts

This passion-based approach likely contributed to confusion among key concepts in the debate. Importantly, the initial policy proposal did not distinguish advanced directives (e.g., “do not resuscitate” orders) from aid in dying (actively hastening death). These changes were subsequently made. Of greater concern was that, in discussions with APHA and OPHA members, terminal illness was often presumed to include severe disability. In discussions that became emotional and personal very rapidly, at least some public health professionals were assuming that severe disability would be included in the category of terminal illness and would be adequate basis for assisted dying.

I might want it for myself

A theme that often emerged in the discussions with public health professionals was “I might want it for myself”. This proposed policy clearly had highly personal meaning for many involved in the discussions. This is consistent with national polling results [1,2] where, depending on wording of the question, about half of the public will support physician-assisted dying. Many people want the option of a hastened death under some circumstances in their abstract personal future. Yet, few will ever exercise that option when it is available. The Oregon annual reports [6] show that after a decade of the Death with Dignity Act, it is exercised by less than 90 people per year, and accounts for less than 16 per 10,000 annual deaths in Oregon. While one must meet criteria to be eligible for this option, its popularity still seems based more on potential use in an abstract future, than on likelihood of actual use.

It’s about control and not about pain

The language of Oregon’s Death with Dignity Act and the resolution before APHA was based largely on management of suffering of adults who are terminally ill—“a fraction of dying persons confront a dying process so prolonged and marked by such extreme suffering that they determine hastening impending death is the best alternative” [7]. Yet in implementation of the Death with Dignity option in Oregon, less than a quarter of people who requested a prescription for lethal medication cited pain as the primary reason for their request. Instead, the reason cited by 9 of 10 persons was “loss of autonomy” and the inability to engage in activities that are enjoyable [6]. Physician and family reports are consistent—individuals want physician assistance to die in order to be in control of their body and of their death [8]. The functional limitations and dependence on others are regarded as so intolerable, that some believe they

would rather die than experience such lack of bodily control. Yet many people with disabilities live every day of their lives with functional limitations that require dependence on others for personal assistance, and many do so while experiencing a good quality of life [9].

The slippery slope and other arguments

An activity I engaged in was to review the arguments against the resolution and examine the research support relating to each argument. This catalogue of concerns was compiled from previous testimony before various groups, solicited input from the Disability Section members, and comments from disability organizations [3,10]. Arguments could be grouped into several broad categories:

- Difficulty with implementation of aid in dying legislation (inaccuracy in predicting that death would occur within 6 months, difficulty in screening out depression)—this concern was based largely on citations to several anecdotal cases.
- Disproportionate use of assisted dying by vulnerable groups (women, people in poverty, people with disabilities, un/underinsured, people in reactive depression, people with chronic mental health conditions)—review of practice in Oregon and the Netherlands [11] provided little support for these fears, but emphasized the need for clear safeguards and careful data collection, including adding a measure of preexisting disability status.
- Negative impact on end-of-life care (decreased quality of palliative care, increased acceptability of suicide in elders; increased assisted dying for nonterminal disorders; decreased reporting by physicians)—there were mixed findings on this concern [12,13].
- Negative impact on social perceptions of disability (sustain or increase negative societal perceptions of persons with disabilities; decreased likelihood of funding for adequate health and long-term care of people with disabilities)—this argument proved the most difficult to demonstrate but became the most powerful and pervasive concern as the debate progressed.

Arguments on the basis of “the slippery slope” often seem weak. They allow that the situation isn’t obviously harmful yet but that, because it *might* become sufficiently harmful, actions need to be taken to guard against that eventuality. In the case of aid in dying, what was revealed were broadly held perceptions that life with severe disability was not worth living. The arguments of at least some proponents of assisted dying were based in the presumption that life without autonomy was not worth living and, therefore, that society should sanction the right to end one’s life under such circumstances. This was evidenced when the resolution was debated by the APHA

Governing Council in 2007; one councilor expressed his confusion and asked for clarification on the position of the Disability Section—he indicated that he had presumed the Disability Section was *sponsoring* the resolution.

Undue burden on people with disabilities

As noted by an Oregon public health official, the Death with Dignity Act was not initiated by public health—it came to public health. Other writers have advocated that professional organizations take a position of studied neutrality on this issue [14]. In 2001, Kass [15] introduced an ethical framework for considering public health actions that I believe should have been applied to the aid in dying policy resolution when it came before APHA. A question to be answered within the Kass framework is, “Does any one group bear a disproportionate share of the burden of this policy’s implementation?” I came to believe that the answer is affirmative; that persons with significant disabilities are unduly harmed by the values that such a measure endorses. Because aid in dying is used primarily to address loss of autonomy and not pain management, and because proponents argue that severe disability should warrant the right to end their life, this suggests a devaluing of a life lived with significant functional limitations.

Policies and laws that support the legal right to die under conditions of functional dependence reflect a form of discrimination—“ableism.” If society endorses the right of a person to seek physician assistance to end his or her life because of increasing loss of functional autonomy, what does that say about how our society values the lives of people who live with comparable limitations every day of their lives for years on end? It begs the question whether there is any other group, based on poverty or race or gender, to whom we would say, “If your life comes to this, we support you in ending your life”? It seemed that was the very issue being debated. It raised questions about the implications for investing in improved health care access or personal assistance supports for persons who are dependent on others for their basic care. One member of the APHA Disability Section who uses a wheelchair summarized this aptly: “I’d like to have the option of physician-assisted dying for myself. But because that position risks devaluing the life that people like me have, I have to oppose it.”

Conclusion—Final reflections on the debate

Our second round of efforts was less successful in opening the dialogue or broadening opposition to the resolution. The APHA Governing Council passed the “Patients’ Rights to Self Determination at the End of Life” resolution in October 2008. Perhaps the Disability Subcommittee could have argued more persuasively and strategically to the larger public health community if we had not been caught up in our own passions and perspectives. Perhaps

the issue is so emotionally charged that it was not possible to have a more thoughtful dialogue within a political format. Perhaps the vote reflected the majority view within the American public. Regardless, it appears that individuals will continue to hold their personal positions, and do so passionately.

The activities of the Disability Section led to some important modifications within the resolution. In the final form of the resolution, advanced directives and availability for improved palliative care were clearly distinguished from aid in dying. A semantic middle-ground between “death with dignity” versus “physician-assisted suicide” was reached with the term “aid in dying.” The form of the resolution finally put to vote used much less incendiary language to argue the case for aid in dying, and it represented the research in a more balanced and accurate manner. Perhaps most important, the final form of the resolution called for the inclusion of a measure of preexisting disability for future states’ implementation.

Through the process, I clarified my own views on aid in dying, both from my perspective as a public health professional and my personal views. It is my view that public health should have taken a position of studied neutrality on aid in dying, similar to some other professional organizations. While the OPHA essentially did so, the APHA did not. Aid in dying is not an issue on which public health needed to take a position, and taking the position it did exacerbated the rift between the disability community and formal public health. Further, we all missed an opportunity for dialogue on the fundamental issues of valuing human life with functional limitations, and understanding its implications in terms of social values and ethical practices. Paradoxically, while the APHA vote supported aid in dying, my personal values were clarified as lying in the other direction. Through this intensely emotional process, I gained greater comfort with my own mortality and the self-knowledge that, for me, loss of my functional autonomy does not need to lead to loss of dignity or hastening of my own death.

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References

- [1] Pew Research Center for the People and the Press. More Americans discussing and planning end of life treatment: strong public support for right to die (Jan 5, 2006). Available at: <http://people-press.org/reports/display.php3?ReportID=266>.

- [2] Gallup poll. Public divided over moral acceptability of doctor-assisted suicide (May 31, 2007). Available at: <http://www.gallup.com/poll/27727/public-divided-over-moral-acceptability-doctor-assisted-suicide.aspx>.
- [3] Golden M. Personal communication, comments from a disability advocacy perspective on APHA's Death with Dignity Policy Proposal: summary of Executive Committee Actions, Disability Rights Education and Defense Fund (October 24, 2007).
- [4] Drum CE, White G, Taitano G, et al. The Oregon Death with Dignity Act: results of a literature review and naturalistic inquiry. *Disabil Health J.* 2010;3(1):3-15.
- [5] Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA.* 2004;291(1):88-93.
- [6] Oregon Department of Human Services. Death with Dignity Act Annual Reports, 1999-2008. Available at: <http://www.oregon.gov/DHS/ph/pas/ar-index.shtml>.
- [7] American Public Health Association. Policy D.1 Patients' Rights to Self Determination at the End of Life (2008). Available at: <http://www.apha.org/NR/rdonlyres/2B1CC75D-FFA6-4FCB-B630-929403F16946/0/D1June08Resubmission.pdf>.
- [8] Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA.* 2000;284(19):2476-2482.
- [9] Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med.* 1999;48(8):977-988.
- [10] Coleman D, Gill C. Testimony before the Constitution Subcommittee of the Judiciary Committee of the U.S. *House of Representatives.* April 29, 1996. Available at: <http://www.notdeadyet.org/docs/house1.html>.
- [11] 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;33:591-597.
- [12] Fromme EK, Tilden VP, Drach LL, et al. Increased family reports of pain or distress in dying Oregonians: 1996-2002. *J Palliat Med.* 2004;7(3):431-442.
- [13] Cassel CK, Ludden JM, Moon GM. Perceptions of barriers to high-quality palliative care in hospitals. *Health Aff.* 2000;19(5):166-172.
- [14] Quill TE, Cassel CK. Professional organizations' position statements on physician-assisted suicide: a case for studied neutrality. *Ann Intern Med.* 2003;138(3):208-211.
- [15] Kass NE. An ethics framework for public health. *Am J Public Health.* 2001;91(11):1776-1782.