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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