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CORRESPONDENCE

Debating "Death with Dignity"

Courtney Campbell's essay "Ten Years of 'Death with Dignity'" [Fall 2008] is an honest assessment by an avowed opponent of Oregon's groundbreaking law. We respect Professor Campbell's moral opposition to what he considers the "taking of human life," and appreciate his respect for patients who make choices based on *their* values, not someone else's. Compassion & Choices agrees with Professor Campbell that opponents' predicted negative impacts have not come to pass. In fact, the law is credited with vastly improving Oregon's end-of-life care across the board.

But we cannot agree with Professor Campbell that the public lacks information about the process that exists under Oregon's Death with Dignity Act or about the people who request aid in dying. Over ten years, an aggressive Oregon media has delivered context and transparency with numerous human interest stories, interviews, chronicles of patient and family experiences, and even a video diary in which Ms. Lovelle Svart shared her most intimate symptoms and thoughts on the website of the state's largest daily newspaper as her cancer progressed over many months. Compassion & Choices contributed to the literature with our own book of stories (*Compassion in Dying: Stories of Dignity and Choice*, 2003) featuring seven essays gleaned from interviews and patient journals and many short vignettes.

Academia has also contributed enormously to the information pool from Oregon. In fact, practice under the Oregon Death with Dignity Act is more studied than any other end-of-life decision, anywhere in the nation. We know who makes requests, what they are dying of, how old they are, and their sex. We know fear of losing control of bodily functions drives them and money is not their concern. We know how they describe their reasons for pursuing death with dignity. We know how many are in hospice care (almost all) and how they compare with similar patients who don't request aid in dying.

We know how much time passes from their first request to their death, from ingestion of drugs to unconsciousness, and from unconsciousness to death. We also know much about patients who make a request, obtain a prescription, never take it, and die naturally.

We know how hospice nurses rank patients under the Death with Dignity Act in comparison with other, non-requesting patients, and we know the same for hospice social workers. We know the conclusions doctors reach about requesting patients and their families.

We also know all about the participating doctors. We know their attitude toward death with dignity, compared with doctors in other states. We know what kind of medicine they practice, how long they have treated their patients under the Death with Dignity Act, how many requests they receive, and what proportion they grant.

And now, further testimony to the exhaustive examination of every facet of the practice, we know researchers received open access to a stunning 178 patients, and of those, they judged three to be depressed, though completely capable of making health care decisions. Campbell cited this study but did not mention that Dr. Ganzini admitted that her findings of depression were inflated by attributing all symptoms (even weight loss and decreased appetite) to depression and not to the cancer or other disease that was killing the patient.

We know about this one particular end-of-life decision in exquisite detail, but that knowledge exists in a vacuum, because we know very little about the decision-making process for other interventions that are just as certain to impact the time of death. What about the choice to stop kidney dialysis, which also brings an intended death? What about the choice to discontinue respiratory support or feeding tubes? Who is making those decisions and why? Are those people depressed? Motivated by suffering? What other options do they consider?

We agree with Professor Campbell that public education is needed in Oregon and elsewhere, but it should be comprehensive enough to help prepare patients and families to make any of the myriad end-of-life decisions that determine how people die in America.

Barbara Coombs Lee
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Courtney S. Campbell's article provides valuable insight about the Oregon Death with Dignity Act (ODDA). Most notably, it illustrates the shift in attitudes that has taken place in the time since Oregon transformed assisted suicide from a crime into a medical treatment.

Professor Campbell noted this change in his description of his university students' attitudes about the ODDA over time:

> Prior to its passage, students in biomedical ethics courses considered the ODDA a "burning issue," a "hot topic," one that made for a good debate, and a subject for which there were commonly significant differences in opinion. And student engagement with the issue, as evidenced by the number of related term papers, ran broad and deep. By contrast, today's students, ten years after the ODDA's implementation, have been acculturated to a "right to death with dignity" as just "the way things are." They find it difficult to see the issue as morally or professionally relevant, and they commonly wonder what "the problem" is with the other forty-nine states and why, after more than ten years, Oregon is still the only state with such a law.

Student attitudes exemplify the ease with which society moves from considering an act appalling to a stance in which that same act is viewed as appealing—or, perhaps more alarming, the way in which something once considered an important "hot topic" rapidly devolves into something "eliciting a 'ho-hum,'" as Professor Campbell puts it.

Unfortunately, while he clearly states that he believes the ODDA was a moral mistake, Professor Campbell accepts the claim made by assisted-suicide proponents that there have been no real "consequentialist" problems resulting from the ODDA. In arriving at that conclusion, he relies on information contained in official annual reports based on data provided by the same physicians who are prescribing the lethal overdoses. While he does note that there may be a problem with information about patient motivations, he seems to assume that information contained in official annual reports (such as the number of assisted-suicide deaths that take place or the seeming lack of complications associated with those deaths) is accurate.

He states that there have been 341 deaths under the ODDA, when all that can be said with certainty is that there have been 341 *reported* deaths. The actual number could be far greater. From the time the law went into effect, Oregon officials in charge of formulating annual reports have conceded that "there's no way to know if additional deaths went unreported" because those officials have "no regulatory authority or resources to ensure compliance with the law." Equally unreliable are the statistics indicating that there have been no abuses or complications. The state has to rely on the word of doctors who prescribe the lethal drugs for such information. Referring to physicians' reports, the state's reporting division explained, "We assume, however, that physicians were their usual careful and accurate selves." Hardly a reassuring statement.

Professor Campbell would have been well served if he had read the excellent article "Physician-Assisted Suicide in Oregon: A Medical Perspective" by Drs. Herbert Hendin and Kathleen Foley published in the *Michigan Law Review* (June 2008). Hendin is CEO and Medical Director of Suicide Prevention International and Professor of Psychiatry at New York Medical College. Foley is Attending Neurologist at Memorial Sloan-Kettering Cancer Center as well as Medical Director and Professor of Neurology, Neuroscience, and Clinical Pharmacology at Cornell University's Weill Medical College. They wrote that the seemingly reasonable safeguards for the care and protection of terminally ill patients written into the ODDA are being circumvented. The problem, they said, lies primarily with the Oregon Department of Human Services which is charged with monitoring Oregon's law and issuing annual reports since the ODHS does not collect the information it would need to effectively monitor the law. They explained that the ODHS "acts as the defender of the law rather than as the protector of the welfare of terminally ill patients."

According to the *Oregonian*, the state's largest newspaper, the reason for the lack of transparency in the ODDA's operation is that a "coterie of insiders run the program, with a handful of doctors and others deciding what the public may know." Those insiders and doctors are primarily officials and health care providers associated with Compassion & Choices (C & C), the assisted-suicide advocacy group that sponsored the ODDA. C & C states in its own records that it has been involved in more that 70 percent of the deaths under the ODDA. Certainly, this should raise at least some questions about the validity of assertions that all is working well under the ODDA.

Rita L. Marker
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Courtney S. Campbell responds: It is revealing of the continuing polarization of opinion over physician assistance in suicide that my recent *New Atlantis* essay is criticized by both principal proponents and principal opponents of the ODDA. I appreciate the challenges raised by both Ms. Coombs Lee on behalf of Compassion & Choices and Ms. Marker on behalf of the International Task Force on Euthanasia and Assisted Suicide; more than that, I appreciate the work they and their respective organizations are engaged in—ultimately, I believe, with the common cause of seeking to ensure that terminally ill patients receive respect, care, and compassion, and that they retain both control and dignity. Our disagreements are largely those of means and methods, not of ends and goals.

The common thread in both criticisms centers on issues of the completeness and reliability of information: Ms. Coombs Lee uses a rhetorical mantra of "we know" thirteen times in support of her claim that medical practice under the ODDA is more comprehensively studied than any context for end-of-life decisions in the country. Ms. Marker, by contrast, treats the annual reporting of information of patient data and demographics by the ODHS with considerable reservation and skepticism, suggesting we don't *really* know what is transpiring under the ODDA.

Can it be that we both know much and yet not enough about the landscape of assisted suicide in Oregon? I share Ms. Marker's concerns about the reporting methodology of the ODHS, and said as much in my essay, but there is little or no evidence of the unreported deaths, physician abuses, patient complications, and political-professional conspiracies that so concern Ms. Marker. Conjecture is an insufficient ground for moral appeals, and in the absence of such evidence of moral scandal, I do not share Ms. Marker's basic distrust of the medical profession and the political bodies responsible for oversight. I have talked with several physicians and many family members who have had patients and relatives use the Oregon law to bring about their deaths; not only have I seen no fire, I haven't yet caught a whiff of smoke.

I agree with Ms. Coombs Lee that there have been extensive studies of participating (and non-participating) physicians dating back to 1994, as well as analyses of pharmacists and hospice professionals. But, with very few exceptions (and I acknowledge the contribution of her organization's book *Compassion in Dying*, which I rely on in my courses in biomedical ethics and in death and dying), the nature of the patient experience has not been transparent. I simply disagree that we can infer from what physicians report on the ODHS form that the public is receiving an accurate reflection of the existential experience of dying patients as they face their own mortality. The point of the ODDA was to empower, not silence, terminally ill patients, and transparency and accountability in a democratic society should allow us to hear patients in their own voices, not the rigid categories of political bureaucracy or physician interpretation. That is simply and ironically paternalism contrary to the fundamental purpose of the ODDA.

I do find myself puzzled by the interpretation presented by Ms. Coombs Lee of the Ganzini, Goy, and Dobscha study published in *BMJ* in October 2008. She writes that the authors had "open access to a stunning 178 patients, and of those, they judged three to be depressed." The article, by contrast, indicates that "of 178 Compassion and Choices clients notified" about the study, 47 (or 28 percent) enrolled, and 12 were ineligible or deceased. (An additional eleven were referred by outside clinicians, bringing the study total to 58.) That leaves 119 clients who apparently refused to participate in the study. It cannot be claimed that the authors of the *BMJ* study had "open access" to a "stunning" 178 patients; the study group had a sample of 58 patients, not 178.

Moreover, of the 58 participants, fifteen patients, not three, met the study criteria for clinical depression. Three of the fifteen patients assessed by the authors as experiencing depression received a prescription for a lethal drug, even though "none had been evaluated by a mental health professional before participation in the research." Ms. Coombs Lee's assertion that there were three depressed patients in a study group of 178 persons is thus misleading; there were fifteen persons diagnosed with depression in a study group of 58, and three persons in this group of fifteen received a lethal drug and subsequently ingested it. The experience of depression does not imply a complete compromise of decision-making capacity, I quite agree, but at a minimum it signals the need for further attentiveness by both professionals and researchers.

Ms. Coombs Lee questions why we have devoted so much attention to the decision-making processes, physician assessments, and regulatory oversight of the ODDA but don't apply the same rigor to patients who refuse or stop life-prolonging medical treatment in the knowledge that such a decision will inevitably bring on their deaths. It's a fair question, but buried in the question is a fundamental philosophical and ethical assumption with which I disagree—namely that decisions about refusal of medical treatment and decisions about hastening death by medical means are morally equivalent. As I've argued elsewhere, I think that an independent moral case has to be made for hastening death by medicine, rather than subsuming all end-of-life choices under one moral category.

Obsolete Librarians

Christine Rosen's "People of the Screen" [Fall 2008] masterfully outlines the plight of the book. Her discussion of the Kindle serves as Exhibit A in what she rightly calls our "increasingly distractible, impatient, and convenience-obsessed" culture.

At the school library where I work, we were recently visited by a sales representative from Follett, a book vendor. I've been putting him off for more than a year now because I'm not up to repeating my habitual lament about the lack of readership in my library any more than he's up to confessing he is two paces behind the encyclopedia salesman on the path to obsolescence. We discussed the sorry state of my bulk print orders, and before falling into a mutual funk, he pulled a rabbit out of his hat: *Charlotte's Web* converted to a Playaway digital audiobook. The cost? $37.95, which is $30 more than a new copy of the print book.

The annual American Library Association conferences reflect the same glee and excitement for the latest new reading gadgetry, the hottest gizmo that promises to light everyone's eyes on fire but not necessarily anyone's brain. Beyond the book publishing aisles, the conference halls throb with the electronic tools of techno-learning: flat screens, inflatable screens, hypertext screens, and an entire line-up of toys designed for "reducing our launching time and optimizing preferences."

Judging from the Follett salesman's bag of e-goodies and my annual professional conferences, the work of libraries is no longer centered on the book. But as Ms. Rosen points out, writing of the University of Michigan study published in the *Harvard Educational Review*, "only reading novels on a regular basis outside of school is shown to have a positive relationship to academic achievement." So, if the school library—the purported hub of learning—is not about the book any longer, then what indeed is our purpose?

When Henry Adams visited the Great Exposition of 1900 in Paris, he bee-lined to the electric turbines, which he suspected would shape the twentieth century as steam power had shaped the nineteenth. Adams understood well the power shift that stood before him. The electronic dynamo promised an even more intense social and cultural disorientation than anything that had preceded it. Today, it is the Kindle and the myriad other marketplace widgets that serve as supreme symbols of disruptive change.

These electronic marvels, the dynamos of our own day, pose a nagging question: How do we apply their power? Is there one Kindle salesman—one librarian, for that matter—who can tell us where these innovations are taking us? Would today's reader-turned-consumer-searcher perhaps be better served by unleashing a subtler power—the power of ideas on the printed page?

The National Endowment for the Arts has just released its latest report, *Reading on the Rise: A New Chapter in American Literacy* (dated January 2009). The report states that the reading of fiction is on the rise after a quarter-century decline. This rebound, if real and sustained, is cause for celebration. But there is reason aplenty to remain wary of the Kindle and its ilk. However astonishing the technology behind any device that promises to enhance the joy of reading, the technology is a distraction—and often a pricey one at that. What makes the reader wiser and improves his well-being is not the toy, but the word itself.

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Christine Rosen responds: I appreciate Mr. Washington's thoughtful letter, and I am heartened to learn that some librarians continue to see themselves as guides to that most astonishing resource—the printed word—and not merely screen-savvy "information specialists." The NEA's recent report, *Reading on the Rise*, does indeed bring good news: The percentage of adults who engaged in literary reading (defined as a novel, short story, or play, read in print or online) in 2008 rose for the first time since 1982. The absolute number of readers (112.8 million) is the highest in the survey's history. Many people have speculated about the causes of this rise—the success of the Harry Potter and Twilight series, Oprah's book club, and the NEA's own "Big Read" program, for example—but lest we become too complacent about reading, we should note that the number of people reading drama and poetry continues to decline. And despite the survey's sunny outlook, the gains still leave a lot to be desired: 49.8 percent of adults in this country don't read literature in their spare time. Despite the clear benefits of immersive reading, television viewing remains Americans' favorite leisure activity. In this climate, it is still important to calculate the costs accrued to a culture in thrall to the screen.