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Final Questions and Comments from a Physician Assisted Suicide Researcher

_Viewpoint

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Since the beginning of my professional career, my research has been motivated by a desire to eliminate unnecessary human suffering, whether in the context of end-of-life decision making, or the regulatory barriers to the treatment of pain (1). This summer, the Journal of Law, Medicine and Ethics, will publish my final article on the Swiss model of assisted suicide and explore its potential for demedicalizing the way we die (2). This publication will also signify the end of my research in assisted death, a research interest that has spanned well over a decade. While such a decision will enable me to focus more of my efforts on opioid risk management (3), assisted suicide will continue to remain a topic of considerable interest to a variety of audiences and stakeholders. This is certainly the case with the Swiss model of assisted death. Consequently, in the interest of encouraging further research and debate on the Swiss model and the regulation of assisted suicide, I would like to pose a research question along with a brief commentary on the need for researcher objectivity and respect for a society's chosen way of life (and death for that matter).

The Right to Die is Broader in the U.S. than in Switzerland?

The so-called right to die in the United States is not a traditional right in the legal sense, but rather represents a variety of laws related to individual autonomy in the context of end of life decision making (2, 4). Physician-assisted suicide (PAS), a procedure where a person receives a lethal prescription from their physician for the express purpose of hastening their own death, is but one choice among many at the end of life (2). While assisted suicide in the United States was a product of the right to die movement, such is not the case in Switzerland. Accordingly, one question that I was never able to explore concerned the impact of Oregon's definition of end of life when compared to Switzerland's. Specifically, could Oregon's reliance on the statutory definition of «terminal illness» in their physician-assisted suicide statute actually expand the «right to die» in the United States when compared to Switzerland's definition of end-of-life? For instance, in Oregon, a terminally ill adult resident may obtain a lethal dose of medication from a licensed physician for the purpose of hastening their own death (5). A person is considered to be terminally ill if their terminal disease is «incurable and irreversible... has been medically confirmed and will, within reasonable medical judgment, produce death within six months» (6). Individual pain and suffering are not a requirement, and in fact, surveys have

often indicated that individual pain is not the primary motivation for seeking PAS; concerns over autonomy and personal dignity are often the root motivations for seeking assisted death (7-8). Consequently, once an Oregon resident is diagnosed as being terminally ill, and complies with the statute's other requirements (e.g., two oral requests and one written request within a fifteen day period), the Oregon resident is eligible to hasten their death immediately (5). Therefore, under Oregon's statutory scheme, a person is considered to be at the end of life (and thus eligible for assisted death), when they have less than six months to live. Switzerland, as we shall see, has a much narrower definition of what constitutes end-of-life. Although Switzerland has many similarities with the Oregon model (5), there are also several key differences. Switzerland, for example, does not have an assisted suicide statute with an accompanying regulatory scheme (5). Secondly, unlike the United States, assisted suicide did not stem from a right to die movement, but was rather one of historical significance unrelated to end of life concerns (9). Moreover, Swiss law does not require that the person providing assistance be a physician. In fact, most assisted suicides are facilitated by non-physician members of private right to die societies such as Exit (5). And while the Swiss do not require that the person seeking assistance be terminally ill (as Oregon law requires), Exit requires that the person seeking assisted suicide be experiencing «unbearable suffering or be disabled in a serious manner» (5). Moreover, according to the Swiss Academy of Medical Sciences (SAMS), «end of life» refers only to «the last few weeks of a patient's life» (not the last six months as in Oregon). SAM's definition was arrived at after a great deal of debate and revision within the medical community and remains an integral part of their guidelines (10). So, if a terminal diagnosis is an essential requirement for assisted suicide in Oregon, not on the existence of unbearable suffering as it is in Switzerland, could one not argue that despite the criticisms of the Swiss model, the Oregon model actually permits an earlier death than in Switzerland which in turn expands the right to die in Oregon through its reliance of terminal illness as a necessary pre-requisite (not unbearable pain and suffering

Objectivity and Respect

nor the last few weeks of a patient's life)?

Aside from posing the above research question, I would also like to briefly comment on the need for research objectivity and respect for a society's way of life (and death). Throughout the past decade, I have read a myriad of journals and books

on assisted death. While most of the published studies have been of high caliber, and published by respected researchers in the field, there have also been many occasions where I could successfully predict the study's results just by knowing who the author was (11). While results reported by self-serving politicians or a sensationalist press are predictable (12), such advocacy or biased reporting by empirical researchers undermines our credibility and our ability to inform public debate and policy. As empirical researchers, we must strive for objectivity (13), not advocacy; otherwise, our work will be perceived as nothing more than opinion.

Finally, and related to the goal of objectivity, is the need for researchers to respect the society they study and that society's way of life and death. Throughout my research, I have read works, often in book form, that criticize a society's beliefs and what the author would characterize as the society's disrespect for life. Who are we to criticize a society and its belief system? One can understandably criticize a government's response, or lack of response, but it seems wholly inappropriate for a researcher to lambast an entire culture. This certainly appears to have been the case with the myriad of criticisms aimed at the Dutch or Oregon models of assisted death. These researchers were able to gain the trust of their research participants who in turn provided information in an effort to help us understand how the system worked (or failed to do so). Yet when the information was subsequently reported, it was delivered in much the same way an opponent or politician would - using selective evidence to bolster their claim while ignoring information to the contrary. And while we may not agree with the way a society conducts its business, we must also recognize that our research participants have also trusted us in the process of discovery. While we must be critical in our evaluation of the data, when it comes to reporting that information it should be done in an objective manner but in a way that remains sensitive to the culture and people under study. Researchers in assisted death, or any other area for that matter, must not further their own, or their organization's agenda to achieve some selfish end. Leave that for the often polarizing politicians or the sensationalist media.

Research in assisted suicide remains controversial, but extremely valuable in terms of life and death, public debate, policy, and clinical practice. The Swiss model of assisted death remains unique, and many more questions than answers remain. But as we explore those many questions, we should strive for objectivity, and be respectful of those who have shared their lives, and at times deaths, with us.

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