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The case for physician assisted suicide: how can it possibly be proven?

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In her paper, *The case for physician assisted suicide: not (yet) proven*, Bonnie Steinbock argues that the experience with Oregon's Death with Dignity Act fails to demonstrate that the benefits of legalising physician assisted suicide outweigh its risks. Given that her verdict is based on a small number of highly controversial cases that will most likely occur under any regime of legally implemented safeguards, she renders it virtually impossible to prove the case for physician assisted suicide. In this brief paper, we suggest some ways that may enable us to weigh the risks and benefits of legalisation more fairly and, hopefully, allow us to close the case for physician assisted suicide.

On November 8, 1994, the US state of Oregon passed the Death With Dignity Act permitting physician assisted suicide. Because of a legal injunction, implementation of the act was delayed by almost three years. After multiple legal proceedings, including a petition that was denied by the United States Supreme Court, the Ninth Circuit Court of Appeals finally lifted the injunction on October 27, 1997. Ever since, Oregon has been the only state in the US where physician assisted suicide (PAS) is a legal medical option.

The Death With Dignity Act (DWDA) allows mentally competent, terminally ill patients who are over 18 years of age and residents of the state of Oregon to obtain a prescription for a lethal dosage of medication to end their own life in case their suffering becomes unbearable. Patients eligible for the act must make one written and two oral requests over a period of 15 days. The prescribing physician and a consulting physician have to confirm the diagnosis and the prognosis. If either doctor believes the patient's mental competence is impaired, he must be referred for a psychiatric or psychological evaluation. The prescribing physician is required to inform the patient of potential alternatives to PAS, such as comfort care, hospice care, and pain control.[1]

Between 1997 and 2004, 208 individuals died under the provisions of the DWDA. In 1998, 16 Oregonians used PAS, followed by 27 in 1999, 27 in 2000, 21 in 2001, 38 in 2002, 42 in 2003, and 37 in 2004. Thus, PAS accounts for only one in 1,000 deaths among Oregonians. Interestingly, about 36 per cent of patients who obtained a lethal dose of barbiturates from a doctor never used it, suggesting that all these patients sought was control over the manner and timing of their deaths. As Timothy E Quill recently put it: ''Perhaps the knowledge that they could end their life if they so desired makes them feel less trapped—and therefore freer to keep going''.[2]

The most frequently reported reasons for choosing PAS under the DWDA are ''loss of autonomy'' (87%), ''loss of dignity'' (80%), and ''loss of the ability to enjoy the activities that make life worth living'' (84%). Concerns about being a ''burden on family and friends'' (36%), ''fear of excruciating pain'' (22%), and financial problems (3%) are surprisingly low. Of the 208 patients, 196 died at home; only one died in an acute care hospital.

Opponents of the act predicted that the patients most likely to avail themselves of PAS would be the poor, the ill educated, and the uninsured who are without access to adequate hospice care.[3] According to the Oregon Department of Human Services, however, which monitors compliance with the DWDA, the overwhelming majority of patients seeking physician assisted suicide are financially well off, highly educated, and have health insurance. On average, 86 per cent of patients using the act are enrolled in hospice care. As a matter of fact, it seems that the legal option of PAS may actually have contributed to the improvement of end of life and hospice care in Oregon. As the Oregon Department of Human Services points out:

> While it may be common for patients with a terminal illness to consider physician assisted suicide, a request for a prescription can be an opportunity for a medical provider to explore with patients their fears and wishes around end of life care, and to make patients aware of other options. Often once the provider has addressed patients' concerns, they may choose not to pursue physician assisted suicide. The availability of assisted suicide as an option in Oregon also may have spurred Oregon doctors to address other end of life care options more effectively. In one study Oregon physicians reported that, since the passage of the Death with Dignity Act in 1997, they had made efforts to improve their knowledge of the use of pain medications in the terminally ill, to improve their recognition of psychiatric disorders such

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Abbreviations: PAS, physician assisted suicide; DWDA, Death with Dignity Act; FLSMT, forgoing of life-sustaining medical treatment; WTWER, withholding or withdrawing of life sustaining medical treatment without the patient's explicit request; VAE, voluntary active euthanasia

as depression, and to refer patients more frequently to hospice.[4]

Although Bonnie Steinbock concedes that the dire predictions of a wholesale abuse of Oregon's DWDA have clearly been proven wrong, she remains sceptical as to whether aid in dying really justifies a sea change in medicine and law. In her paper, *The case for physician assisted suicide: not (yet) proven*, she concludes: ''I am not suggesting that the Oregon law should be repealed. […] My point is rather that before the rest of us climb on the PAS bandwagon, there are many crucial issues to be hammered out. The discussion should continue. At present, the case for legalising PAS seems to me to be still—in the words of the Scottish verdict—not proven.''[5]

The famous Scottish verdict ''not proven'' is usually taken to imply a strong suspicion of guilt, in the absence of sufficient evidence to convict. So what is Oregon's seemingly successful practice of PAS ''guilty'' of? Or, to rephrase the question, why does Steinbock, as she herself puts it, ''remain conflicted''? Apparently, for two reasons. First, partisanship on the issue of PAS makes it extremely difficult to assess the Oregon data objectively. Proponents of PAS interpret the statistics in a strikingly different way from its opponents. And second, there have been several reports about abuses of the Oregon DWDA, suggesting that the existing safeguards do not work. These cases of alleged abuse involve patients who might have been mentally incompetent or clinically depressed. In one of these cases—for example, the one usually referred to as ''Helen's case''—a woman in her mid-eighties with breast cancer had been diagnosed with depression by an internist, but as competent by a psychiatrist. Four additional doctors who were also involved in her terminal care agreed with the psychiatrist and ''considered her psychologically healthy and competent to make medical decisions for herself''.[6] So had the internist's diagnosis of depression consciously and deliberately been ignored, as opponents of Oregon's legislation claim? We do not want to get into this debate. Let it suffice to say that the mere fact that most of the allegations of abuse come from the author of *Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder*,[3] should at least make us pause.[7] What is more, when the British House of Lords visited the State of Oregon to inquire about the reliability of the reporting system and the practicality of the legal safeguards, even the entirely unsuspicious executive director of the Oregon Hospice Association, Ann Jackson, stated: ''Oregon is a very, very small state and we have hospices all over, and they have big mouths! I think if there were any abuses in the law, we would hear of it.''[8]

Although we agree with most of Steinbock's excellent paper, her overly cautious, if not outright disheartening conclusion calls for five critical comments. First, her reference to the old Scottish verdict and her recommendation to other US states not to climb on the PAS bandwagon imply that ''there is something rotten in the state of Oregon''. More specifically, it tacitly assumes that the legalisation of PAS may have put the terminally ill at greater risk. What makes her think, however, that this is really the case? Most likely, the highly controversial claims that there have been a number of abuses in Oregon. Yet even if these allegations were true, we are simply in no position to make the claim that the terminally ill have become more vulnerable since the legalisation of PAS. To demonstrate that, we would need to have at least *two* sets of empirical data: data collected *before* and data collected *after* the passage of the DWDA. Only then would we be in the position to determine whether the terminally ill have become more or less vulnerable. Given that there are no data on the incidence of abuse prior to the legalisation of PAS, we simply cannot claim that the terminally ill are now at a greater risk.[9]

Second, given that her advice that other US states should wait for some more years before jumping on the PAS bandwagon is solely based on the highly controversial claims of abuse, it is simply unwarranted. Does she really believe that waiting for, say, another seven years will actually resolve the controversy over Oregon's DWDA? That is highly unlikely! There will always be claims of abuse. If no one else will, Wesley J Smith will make sure of it.[7] Thus, if other US states that are currently considering legalisation of PAS, such as Vermont and California, were to follow her advice, they would, in all likelihood, never get a chance to pass their own version of a DWDA. Personally, we hope that Vermont and California will follow Oregon's lead. These states might, however, indeed be well advised to implement some additional legal safeguards, such as a mandatory assessment by psychiatrists for all patients seeking PAS. Implementing more stringent safeguards will by no means guarantee that there will not be any claims of abuse, but it may at least reduce the number of wrongful allegations.

Third, by relying on dubious claims of abuse and by attempting to dissuade other US states from following Oregon's lead, Steinbock makes it virtually impossible to prove the case for PAS. If controversial cases are considered as evidence against the practicality of PAS, and if other states are not permitted to enact their own DWDA, how can she possibly expect an ''American verdict'' on the case of PAS?

Fourth, Steinbock appears to be inconsistent in applying her own approach. At the outset, she emphasises that policy decisions ''should *not* be based solely on individual cases, heart wrenching though these may be''. Yet her entire argument is based on two ''individual cases'', in which abuse *might* have occurred! As already mentioned, there is ample reason to doubt that the cases Steinbock highlights did involve any abuses. We do not deny, however, that abuses may, indeed very likely will, occur. No system is foolproof and no legislation without risk. It is, of course, a tragedy if someone capable and desirous of enjoying life meets an untimely death as a result of abuse of PAS legislation, in Oregon or elsewhere; but discovery of such cases would not serve to demonstrate that the legislation is flawed. Abuses will occur under any legislative regime, whether PAS is permitted or not. Steinbock asks us to assess the need for and the risks of PAS. We endorse her call. She, however, has not done this. Which brings us directly to our fifth and final critical comment on her paper.

Although Steinbock adopts a consequentialist approach and suggests that ''we need to assess the *need* for PAS, and weigh this against the *risks* of mistake and abuse'', she does not give us any indication as to how we are supposed to balance the two. Suppose, for the sake of the argument, that the opponents of PAS are right and that there have indeed been several cases of abuse of Oregon's DWDA. Let us say that among the 208 cases of PAS there have been five such cases. Would these five cases outweigh the remaining 203 cases? If not, how about 10 such cases? 15? 20? How many cases of abuse ought to be tolerated before we can say with certainty that the risks of PAS outweigh the need for PAS? Unfortunately, we are not told.

At least in theory, the answer to the question of how many abuses can be tolerated could go like this: we should tolerate the same level of abuse in PAS that we tolerate in forgoing life sustaining medical treatment (FLSMT). Although it is often ignored, FLSMT is as prone to abuse as PAS. Just as the poor, the elderly, the disabled, and the clinically depressed can be subtly pressured into PAS, so they can be subtly pressured into FLSMT. And just as physicians concerned about the costs of medical treatment can subtly pressure

patients into requesting PAS, they can subtly pressure patients into requesting FLSMT.[10] As far as we can see, there is simply no justification for treating the risks of FLSMT any differently from the risks of PAS. After all, in PAS as well as in FLSMT, the result is a non-voluntary death.

Unfortunately, treating the risks of PAS and FLSMT alike is easier said than done. In order to tolerate the same level of abuse in PAS as in FLSMT, we would need to have reliable data on the number of abuses occurring in the context of FLSMT. We do not, however, have any such data. Also, establishing the number of deaths resulting from subtle pressures to forgo life sustaining medical treatment, it seems, is simply impossible.

A more practical way to determine an acceptable level of risk in physician assisted suicide is by relying on comparisons of the incidence of withdrawing or withholding life sustaining medical treatment without the patient's explicit request (WTWER). Although no one fails to mention the notorious ''1,000'' cases of life terminating acts without explicit request found in the Netherlands,[11] hardly anyone acknowledges the existence of the same practice in other countries. A US study conducted in 1998 found—for example, ''that in 15.3 per cent of cases, the patients were not involved in the [end of life] decision but families wanted the patients' lives ended. This lack of involvement even occurred in cases where the patients were conscious and could have participated in the decision.''[12] Similarly, an Australian survey conducted in 1997 ''revealed that in more than 20 per cent of cases Australian doctors hastened their patients' death by withdrawing treatment without an explicit request''.[13] In Italy and Sweden, ''more than 50% of all end of life decisions, whether for competent or incompetent patients, were discussed with neither the patient nor with relatives''.[14]

A recent study comparing end of life decision making in six European countries—Belgium, Italy, Sweden, Denmark, Switzerland, and the Netherlands—indicates that permitting PAS or voluntary active euthanasia (VAE) may actually decrease the number of cases in which doctors withhold or withdraw life sustaining medical treatment without the patient's explicit request: ''In all countries other than the Netherlands and Switzerland, the incidence of life terminating acts without explicit request of the patient was higher than the incidence of physician assisted suicide and voluntary euthanasia on request of the patient. Perhaps an open debate and a tolerant policy are not that bad after all.''[15]

Although we do not have comparable data for Oregon, it is not unreasonable to assume that legalisation of PAS may have appreciably reduced the number of doctor's decisions to WTWER. If so, we certainly have to take this into account when balancing the benefits and risks of legalising PAS. Given that a statistically significant reduction in the number of WTWER might very well tip the scales, we should encourage US states considering legalisation of PAS to conduct surveys measuring the current incidence of WTWER. This way, we can reliably determine whether the legalisation of PAS has or has not reduced the incidence of WTWER.

Let us conclude by advancing some additional suggestions as to how the case for PAS might possibly be proven. As already indicated, assessing PAS is a comparative matter: we need to know what potential there is for abuses under a particular legislative regime, as compared, not only to other legislative regimes that permit PAS, but also to others that ban it. All means of regulating end of life medical treatment have their risks of abuse. Doctors may collude with one another, or maverick doctors may act alone; incompetent patients may pass for competent, and relatives and others might attempt to coerce patients into a premature death. We know that PAS occurs even in jurisdictions that forbid it, but we have little idea of how often it is abused (indeed, how often *involuntary* euthanasia, or murder disguised as PAS or involuntary euthanasia occurs). Since we do not have these comparative statistics—they are, by their nature, difficult to gather—we are not in a position to assess the risks of PAS. Nor are we in a position to assess the risks of *not* having PAS. We note, however, that it is at least possible that legalising PAS reduces the number of abuses, for several reasons: because patients are able to remain rational longer when they do not fear losing control over the timing and manner of their death (recall that more patients request and receive lethal barbiturates than actually use them); because the stricter oversight reduces the potential for abuses, and because doctors respond to requests for PAS by improving end of life care.

Thus, answering Steinbock's call for an assessment of the risks of PAS requires more data than we have. Moreover, even if we are able to gather the relevant data, there remains hard *conceptual* work to do, in weighing the risks against the benefits of the legalisation. How do we go about assessing the risks? What weight are we to place on the loss of hours, days or weeks of life, when we are talking about the life of an incompetent, perhaps delirious, patient who is suffering from pain or depression (all of which are sufficient to make PAS illegal)? This is an extremely difficult question; we note here only that anyone who believes that it is appropriate to take quality adjusted life years into consideration in making decisions about medical treatment seems committed to thinking that these kinds of factors do make a difference here. Against the loss of lives, we need to weigh the benefits gained by PAS, measured in peace of mind, enhancement of autonomy, and forgone pain and suffering. Once again, we have little idea how to quantify these things. Yet assessing the risks and benefits of PAS requires that we have answers to these questions.

Steinbock is right to hold that attention to heart wrenching cases is not sufficient to make the case for PAS. Yet she does not provide us with any suggestions for proceeding. Here we have provided a few such suggestions. Assessing PAS requires a great deal of work, both empirical and conceptual. In the meantime, we have no evidence at all that it is riskier to permit PAS than to forbid it.

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