Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups—another perspective on Oregon's data

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ABSTRACT

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Battin et al examined data on deaths from physicianassisted suicide (PAS) in Oregon and on PAS and voluntary euthanasia (VE) in The Netherlands. This paper reviews the methodology used in their examination and questions the conclusions drawn from it-namely, that there is for the most part 'no evidence of heightened risk' to vulnerable people from the legalisation of PAS or VE. This critique focuses on the evidence about PAS in Oregon. It suggests that vulnerability to PAS cannot be categorised simply by reference to race, gender or other socioeconomic status and that the impetus to seek PAS derives from factors, including emotional state, reactions to loss, personality type and situation and possibly to PAS contagion, all factors that apply across the social spectrum. It also argues, on the basis of official reports from the Oregon Health Department on the working of the Oregon Death with Dignity Act since 2008, that, contrary to the conclusions drawn by Battin et al, the highest resort to PAS in Oregon is among the elderly and, on the basis of research published since Battin et al reported, that there is reason to believe that some terminally ill patients in Oregon are taking their own lives with lethal drugs supplied by doctors despite having had depression at the time when they were assessed and cleared for PAS.

The paper by Battin *et al*¹ titled above purports to examine 'whether there is evidence that, when assisted dying is legal, the lives of people in groups identified as vulnerable are more frequently ended with assistance from a physician than those of the background population'. However, their paper categorises vulnerability by reference to certain socioeconomic groups, relating to age, race, sex and economic and educational status, rather than by reference to emotional vulnerability and personality type, or other recognised markers of vulnerability among people seeking to end their lives, which exist across the spectrum of society.² They conclude that there is no evidence that legalised PAS in Oregon poses a risk to people who are, according to their definitions, vulnerable. We question the validity of this conclusion, as these factors are likely to be invisible to their traditional socioeconomic analysis.

BACKGROUND

A key concern over the legalisation of PAS is that a law enacted to provide PAS for self-reliant and strong-willed individuals with capacity might migrate into the population of terminally ill people as a whole, encouraging less resolute individuals to opt for PAS either as the result of real or perceived pressures from others or from within themselves, or under the influence of treatable and transient depression. Whether this is happening in practice in the US state of Oregon is the question that the study of Battin *et al*¹ sought to answer.

They examined Oregon's data on PAS since its legalisation under the Oregon Death with Dignity Act (ODDA) in an attempt to assess whether persons in certain socioeconomic groups are dying by PAS more often than others in the population at large. The categories selected by Battin *et al*¹ were as follows:

- 1. The elderly
- 2. Women
- 3. Uninsured people
- 4. People with AIDS
- 5. People with low educational status
- 6. The poor
- 7. Racial and ethnic minorities
- 8. People with non-terminal physical disabilities or chronic non-terminal illnesses
- 9. Minors and mature minors
- 10. Patients with psychiatric illness, including depression and Alzheimer's disease

They concluded that all these categories show 'no evidence of heightened risk' in Oregon.¹

THE CATEGORIES

We call into question the methodology used and the conclusions derived from it on four distinct grounds. First, Battin et al's conclusions of vulnerability to PAS among elderly people in Oregon seem at variance with official Oregon Health Department (OHD) data.³ Second, some of the other socioeconomic categories used (in particular, women, racial minorities and people of low educational or economic status) seem to be of questionable relevance in the context of vulnerability to PAS, whereas other vulnerabilities have not been discussed. Third, the distinctions and legal implications are not discussed between terminal illness, which the ODDA covers, and chronic illness or disability for which the ODDA does not license PAS. Finally, we cite more recently published Oregon-based research suggesting that, contrary to the conclusion reached by Battin et al,¹ persons with depression are indeed vulnerable to PAS; we also discuss how vulnerability may be categorised. We deal with these four concerns in turn.

Law, ethics and medicine

PAS and the elderly

Battin *et al*¹ have compared the proportion of deaths from PAS and deaths from other causes for two groups of people in Oregon—those aged 85 years or over, who they define as elderly, and those aged 18–64 years. They report that 'in Oregon 10% of patients who died by PAS were 85 or older, whereas 21% of all Oregon deaths were among persons in this age category'. They state that 'persons aged 18–64 years were over three times more likely than those over age 85 years to receive assisted dying'. From this they draw the conclusion that there is 'no evidence of heightened risk' to the elderly from the legalisation of PAS.

There are a number of problems with this approach. Traditionally, the threshold of the beginning of old age is 65 years, subcategorised by subsequent decades.⁴ Eighty-five years is far too high to indicate the beginning of old age. Second, Battin et al's calculations and comments omit deaths among Oregonians aged between 65 and 84 years, despite the OHD annual reports on the operation of the ODDA since 1998, showing that the majority (60%) of all PAS deaths occur in these demographically recognised decades, 65-84 years, which are usually called elderly. A third problem lies in the method of calculation itself that is vulnerable to a systematic error. Since death rates from non-PAS causes among persons aged 85 years or over are naturally very high, it follows that almost any rate of PAS in this age bracket is likely to show up as proportionately less than the rate of deaths from other causes. Conversely, as deaths from non-PAS causes are relatively less frequent among the young and middle-aged (18-64 years), even a relatively small rate of PAS will loom large in this age group as against other deaths.

The 12 OHD annual reports issued between 1998 and 2009 show that, of the 460 persons who have died in Oregon by PAS over this 12-year period, 314 (68.3%) were aged 65 years or over, whereas 146 (31.7%) were aged between 18 and 64 years. Moreover, the median age for PAS recorded in the reports over the 12-year period is 71 years. Battin *et al*'s conclusion that the elderly are not at higher risk of PAS would appear to be at variance with these official data.

Irrelevant groups

The socioeconomic groups selected by Battin $et al^1$ as measures of vulnerability are commonly used in sociological research to address questions in fields such as employment, education, housing, health (eg, malnutrition) and life expectancy. It is questionable, however, whether many of them can be regarded as indicators of vulnerability in the context of PAS. Conversely, in qualitative research, vulnerability in end-of-life decisionmaking has been shown to be more related to communicative difficulties, situation, having unrelieved symptoms or a distressing medical condition, or being socially undervalued. These factors transcend socioeconomic groupings.² While some of the groupings selected by Battin $et al^{1}$ (eg, the elderly, those with illnesses or disabilities and persons with psychiatric illness) are clearly relevant, there is no explanation offered as to why others such as women, racial minorities, the less well educated or less wealthy should be regarded as vulnerable to taking their own lives through PAS.

Battin *et al*¹ state that 'in Oregon 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide'. Battin *et al*¹ do not say whether women were being compared with men as the PAS data on gender was available or because the hypothesis was that they might have been considered potentially more vulnerable to PAS than men. It is worth noting that studies have suggested that

suicide risk and suicide rates overall are higher among men than women in both the USA and Europe. $^{5\ 6}$

Similarly, we are told that 'in Oregon 97% of the 292 patients who had a physician's assistance in suicide were white'. Given that white individuals comprise some 90% of Oregon's population, this is also unsurprising. Again, Battin *et al*¹ do not state why ethnicity was included in their analysis of the impact of legalised PAS on vulnerable groups. Although members of ethnic minorities tend to be socioeconomically disadvantaged, the linkage is far from being universal. Interestingly, one might expect trends in the other direction, for example, members of ethnic minorities often hold religious or moral beliefs that are unfavourable to the concept of PAS. Their lower access to health care and palliative care in the USA, and mistrust of authority in general, may in fact make these groups less vulnerable to PAS.⁷⁸

Battin *et al*¹ state that 'in Oregon the likelihood of dying by PAS was correlated with higher educational attainment'. They continue: 'Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high school diploma'.¹ Two questions arise from this finding. First, are people who are better educated more vulnerable, in the context of PAS, because illness and potential dependence are more frightening to them or because they have fewer psychosocial supports? Second, perhaps more interestingly, why did the finding that college graduates were 7.6 times more likely resort to PAS than others not lead Battin and her associates to question whether, if the less well educated are not especially vulnerable to PAS, perhaps the better educated are? There is a need to dig somewhat deeper in order to try and establish whether, for example, educated patients may resort more frequently to PAS because they are people who are familiar with the intricacies of the law and can argue more persuasively with their physicians (J Griffiths, personal communication, 2010). Alternatively, they may be vulnerable to factors invisible to rigid demographic analysis.

We are told that 'death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence'.¹ The OHD reports that 2.6% of those dying by PAS cited financial implications of treatment as an end-of-life concern, but only 1.3% had no health insurance of any type, suggesting that perceptions of cost rather than absolute economic disadvantage might influence vulnerability to PAS in a healthcare system that does not provide equitable universal coverage. Yet Battin *et al*¹ do not reflect on the vulnerabilities that wealth may bring, for example, perceptions of suffering, dignity, control, or the stigmatisation of illness and disability. These merit discussion, if only to establish that they are not clear forces towards the desire to die or that the data simply do not exist to confirm or refute hypotheses. There are, however, within the existing more detailed data, pointers that seem to have been overlooked.

The Oregon data on factors such as loss of control, indignity and being a burden suggest that such vulnerabilities cannot be ignored when set alongside the relative prosperity of those resorting to PAS as a solution to their suffering. The authors appear to have seen the concept of vulnerability from one perspective only—as something to which only less educated or less wealthy persons might succumb. In any research analysis or critique, it is necessary to recognise what anthropologists call the 'insider—outsider' polemic in which those who see a problem from within a set of values have difficulty imagining a view from elsewhere.⁹

Battin *et al*¹ do not discuss the ongoing—currently fourfold—rise in PAS in Oregon, but media coverage and possible contagion need consideration.¹⁰ Also, there may be a subliminal unintended coercive influence from proponents of PAS, Compassion in Dying of Oregon, who often broker contact between the patient and prescriber of PAS and who 'guided most of those availing themselves of an assisted death'.¹¹ Coercion is notoriously slippery to unmask, especially in consumerist societies in which citizens may be more sensitive to fashion and the new and when it is all too easy to project one's own view of best interest upon another, or to feel oneself that not to conform to the new way is in some manner politically incorrect.

The sick and disabled

It is important to establish whether persons who are chronically rather than terminallyill—that is who do not meet the ODDA's criterion of a 6-month prognosis of death—are receiving PAS in Oregon. Battin *et al*¹ state that in Oregon 'no one received physician assistance in dying who was not determined by two physicians to be terminally ill'. They concede that 'some patients received lethal prescriptions that they did not ingest and lived longer than 6 months' and observe that this 'may represent limitations in prognostication'.

Indeed, prognostication is notoriously difficult,¹² but other factors need consideration. The statement that no one received lethal drugs who was not terminally ill is based on voluntary declarations by prescribing doctors, who are hardly likely to make such declarations if this key criterion in the assessment process for PAS has not been met. Indeed, the OHD annual reports on PAS repeatedly observe that 'our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the provisions of the Death with Dignity Act'.¹³

As Battin *et al*¹ state, prognosticating is not an exact science. The OHD data from 1998 to 2009 reveal the median length of time between first request for PAS and death was 43 days (range 15-1009 days).¹⁴ Therefore, in at least one instance a patient was issued with lethal drugs by a physician on the understanding that he or she had 6 months or less to live but lived for some 3 years thereafter. This is not to suggest that Oregon physicians are incompetent or breaking the law but rather that the difficulties of prognostication are such that persons who are chronically rather than terminally ill can find themselves inadvertently accessing PAS within the terms of the ODDA.

Some of Battin et al's observations appear to blur the distinction between terminal and chronic illness. They state that 'virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill'; that 'patients who are dying lose functional capacities and may be bedridden towards the end'; that 'in this sense, most patients who received assistance in dying in either Oregon or The Netherlands (which we do not deal with specifically here, but nevertheless informs the Oregon debate) were chronically ill and (recently) disabled'; and that 'cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and The Netherlands, is often identified as a chronic illness'. This begs the question: what definition of chronic illness is being used? The term is normally employed to designate an illness that persists for some considerable time and that may-but will not necessarily-be the eventual cause of death. Therefore, illnesses such as multiple sclerosis, Parkinson's disease and cardiopulmonary disease pretty well universally have a chronic and disabling prelude before they become predictably terminal as defined by less than 6 months to live. Unlike some advanced malignancies, they are not terminal in the sense that they have set the patient on a trajectory to death within a relatively short space of time. While some cancers may go into remission and persist in the background of a patient's life for a number of years, many others come unforeseen and bring about the patient's death within a matter of months or even weeks.

Depression

In referring to psychiatric illness, the authors state that 'approximately 20% of requests for physician assistance in dying [in Oregon] came from depressed patients but none progressed to PAS', that is one in five applicants for PAS in Oregon was diagnosed as having depression and was not allowed to proceed. It does not account for those with undiagnosed depression who proceeded to PAS.

On this crucial, latter question, since Battin et al's paper, a co-author, Ganzini, has published a case-based study of 58 patients who requested PAS, 18 of whom were given clearance for PAS by the assessing physicians. Of these 18, three (ie, one in six) had treatable but undiagnosed depression at the time of their assessment.¹⁵ She concluded that Oregon's Death with Dignity Act 'may not adequately protect all mentally ill patients'. While Battin *et al*¹ acknowledge that 'not all patients who requested assistance were specifically evaluated by mental health professionals', there may be a proper and more urgent cause for concern as this understates the OHD's data on the operation of Oregon's PAS law with respect to psychiatric and psychological assessment. By 2009, only 38 (8.4%) of the 460 people who had ended their lives under the terms of the Act had been referred for psychiatric evaluation, with a drop in referrals in recent years to zero or near zero.¹⁴ Ganzini's empirical data appear to cast doubt on Battin et al's statement that 'there is no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA'.

CONCLUSION

We challenge the underlying assumptions and the methodology chosen by Battin *et al*¹ in their 2007 examination of PAS risks among vulnerable groups. Many of the socioeconomic categories against which the operation of Oregon's PAS law has been tested have little or no relevance to concepts of vulnerability to 'assisted dying'.

Socioeconomic categories are not necessarily a proxy for vulnerability to accessing PAS. The Oregon data demonstrate a greater resort to PAS among better educated and financially affluent persons, particularly those over 65 years of age. This warrants further enquiry to ascertain whether they have vulnerabilities to influence to accessing PAS, which are not adequately addresses in their healthcare system.

More recent research calls into question the conclusion that persons with depression are not being put at risk of PAS. In short, we believe Battin *et al*'s analysis of the data as regards the PAS scene in Oregon is incomplete.

Competing interests IGF and RG have both spoken against changing the law on physician-assisted suicide/euthanasia in the UK. IGF is a Director of Living and Dying Well (not remunerated).

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Law, ethics and medicine

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