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Citation for final published version:

Regnard, Claud, Worthington, Ana and Finlay, Ilora 2023. Oregon Death with Dignity Act access: 25 year analysis. *BMJ Supportive & Palliative Care* 10.1136/spcare-2023-004292

Publishers page: <https://doi.org/10.1136/spcare-2023-004292>

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This article has been accepted for publication in BMJSPCARE following peer review.

The definitive copyedited, typeset version is available online at [10.1136/spcare-2023-004292](https://doi.org/10.1136/spcare-2023-004292)

“Oregon Death with Dignity Act Access: 25 year analysis”

KEYWORDS:

Assisted death; assisted suicide; medically assisted suicide; Oregon; physician-assisted suicide

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ABSTRACT

Objectives: Assisted dying has been legally available in Oregon for 25 years, since when official reports have been published each year detailing the number of people who have used this option as well as sociodemographic and information about the process. The aim of this study was to examine changes over time in these data.

Methods: We collated and reviewed data on 2,450 assisted deaths included in annual reports on assisted deaths published by the Oregon Health Authority from 1998 to 2022. Descriptive statistics were used to describe time trends.

Results: The number of assisted deaths in Oregon has increased from 16 in 1998 to 278 in 2022. Over this time, patients' health funding status changed from predominantly private (65%) to predominantly government support (79.5%), and there was an increase in patients feeling a burden and describing financial concerns as reasons for choosing an assisted death. There has been a reduction in the length of the physician-patient relationship from 18 weeks in 2010 to 5 weeks in 2022, and the proportion referred for psychiatric assessment remains low (1%). Missing data is frequent, particularly around complications.

Conclusions: The number and characteristics of people accessing assisted deaths, and the process, have changed since data collection started in 1998. Prospective studies are needed to examine the relationship between socioeconomic factors and the desire for an assisted death in Oregon.

Word count for main text= 3077

KEY MESSAGES

What is already known on this topic

⇒ Oregon has had assisted dying legislation for 25 years.

What this study adds

⇒ Many aspects have changed with rising numbers, expanding criteria and sociodemographic changes.

⇒ Much of the data on complications is missing and many variables are not collected, especially around decision-making, drug efficacy and the nature of palliative care support.

How this study might affect research, practice or policy

⇒ Oregon's changing trends in assisted dying require detailed prospective studies examining how socioeconomic factors influence the wish for an assisted death.

INTRODUCTION

Since 1998, the Oregon Health Authority (OHA) has published an annual data report. (1) This includes aggregate information on the demographics of those accessing an assisted death, their diagnoses, health funding status, lethal drugs used, patient concerns, the nature and extent of care provided, complications, and the timings of an assisted death.

Assisted dying is a term which in Oregon's legislation covers only self-administered lethal drugs (physician-assisted suicide (PAS)). In other jurisdictions it also covers clinician-injected drugs (euthanasia) or both. (2, 3) In 1997, Oregon enacted the Death with Dignity Act (DWDA). This legislation allows residents of 18 years of age upwards, capable of making and communicating health care decisions, and diagnosed with a terminal illness that will reasonably lead to death within six months, to end their lives through the voluntary self-administration of lethal drugs prescribed by a physician for that purpose. Annually, the OHA publishes an annual report containing data on the implementation of the legislation. The annual data report for 2022 provides the 25th year's data.

The official notification requirements vary between jurisdictions. Official reports contain limited characteristics such as total numbers, patient age or broad summaries, without standardised international reporting. (4-6) Oregon reports are the most detailed, and as some jurisdictions consider 'assisted dying' legislation based on Oregon, it is important to examine trends in a quarter of a century's data from their experience. The aim of this study was to examine detailed changes over time in the data from Oregon.

METHODS

Starting in 2022, we examined the data contained in every PAS report published by the OHA from 1998 to 2021, adding data from the latest 2022 report in March 2023.(1) We manually extracted information on the number of patients who were prescribed PAS drugs under the DWDA, sociodemographic data such as insurance status, information on the motivations for hastening death, the underlying illness which qualified them for PAS, and the number and types of lethal drugs prescribed under the legislation. Data was extracted into Microsoft Excel, which was used to describe data and trends from 1998 to 2022. Percentages and proportions were calculated, and trends examined graphically. Linear trend lines were generated with Excel's graph function.

RESULTS

Change in numbers of participants.

In 1998, 24 prescriptions were written for PAS drugs and 16 patients died from ingesting these drugs. On average, the number of PAS drugs prescribed under the legislation increased by 13% each year and the number of patients who died by ingesting these drugs by 16% annually (Figure 1). In 2022, 431 prescriptions were written, and 278 patients died by PAS. The proportion of deaths following ingestion of prescribed drugs compared to the prescriptions written increased slightly from an average of 58% in the first decade (1998 – 2007), to 66% in the second decade (2008 – 2017); following which it has been stable at an average of 67% over the last 5 years.

Figure 1 near here

Changes in the sociodemographic characteristics and end-of-life care concerns of participants

There has been little change in the mean age of PAS patients of 72.5 years. The proportion of PAS patients aged 75 or more has remained stable being 48% in 2006 and 51% in 2022.

In the first decade of legislation of PAS in Oregon, an average of 65% of participants were privately insured (Figure 1). Since 2008, this proportion has reversed; in 2022, 20.5% of those who died by PAS held private health insurance, while the majority (79.5%) had government insurance through Medicare or Medicaid.

The percentage of PAS patients who cited being a burden on family and friends increased during the time period (Figure 2). The number of patients reporting financial concerns about treatment as an end-of-life concern is low, though there is evidence of an increase over the time period (up to 8.4% in 2021) (Figure 2). In the first five years of PAS, an average of 30% of participants were concerned about being a burden. Since 2017, this concern has been cited by around half of those who die by PAS (46% in 2022).

Figure 2 near here

Changes in patient eligibility

Eligibility under the DWDA requires that patients have been diagnosed with an illness that will reasonably lead to death within six months. Cancer remains the main diagnosis of PAS patients, though the proportion has reduced over the time period from an average of 80% in the first 5 years to 64% in 2022. In 2022, 109 patients (25% of prescription recipients) were granted an exemption from the usual 15-day reflection period on the basis they were terminal. Since 2010, patients with a range of non-cancer diagnoses have received PAS including non-terminal illnesses such as arthritis, arteritis, complications from a fall, hernia, sclerosis, ‘stenosis’ and anorexia nervosa.

Referrals for psychiatric evaluation have declined as a percentage of assisted deaths (Figure 3). In the first three years after enactment (1998-2000), a psychiatric assessment was sought in an average of 28% of cases. By 2003, this had dropped to 5% and in 2022 1% of patients who died from PAS underwent psychiatric evaluation. Since 2010 there has been a reduction in both the median duration of the physician-patient relationship and the time from the first request to the death (Figure 3). In 2010 the median physician-patient duration was 18 weeks dropping to 5 weeks in 2022. The time from the first request to death had reduced from 9.1 weeks in 2010 to 4.3 weeks in 2022.

Figure 3 near here

PAS drugs

From 1998 to 2015, the most common drugs used for PAS were barbiturates, with phenobarbital, secobarbital or pentobarbital used alone. It is now standard for drug combinations to be used, with different combinations being used in the last 8 years (though the dose of each constituent drug is not reported):

2015-2022: DDMAP (diazepam, digoxin, morphine sulphate and propranolol)

2018-2022: DDMA (diazepam, digoxin, morphine sulphate and amitriptyline)

2019-2022: DDMA-Ph (DDMA plus phenobarbital)

The 2022 report states that the combinations have resulted in longer times from ingestion to death (3 mins-68 hours; median 52 minutes), compared to an aggregate range of 1-104 hours; with a median of 30 minutes over the 25 years. The number of prescriptions per doctor has increased from an average of 1.6/doctor in the first five years to 1998 to an average of 2.7/doctor between 2018 to 2022 (Figure 4).

Stated complications following the ingestion of PAS drugs have included difficulty in ingesting drugs, regurgitation, seizures, regaining consciousness and ‘other’ complications that are not described.

Complications associated with PAS drugs were reported in an average of 11% between 2010 and 2022, with a peak of 14.8% in 2015 (Figure 4). In 2022 complications were identified in 6% of patients, though data on complications was missing in 206 patients (74%). Over the last 25 years, 9 patients have regained consciousness.

In Oregon in 2022, 46% of patients did not take their prescriptions. Of these, 84 died of other causes. In 101 patients the ingestion status was not known, only that 43 died. In 58 the status of death and ingestion was unknown at the time of the report.

Figure 4 near here

DISCUSSION

Number of deaths

The 25 years of OHA's official data reports show that the number of assisted deaths rose slowly for the first 15 years following legislation, then accelerated. When this is considered as the prevalence of PAS deaths overall, the trend is confirmed, with an increase in 2014 from 0.06% (1998) to 0.24% (2012), a slight drop in 2013 to 0.22% then a steeper rise of 0.66% in 2020 when reporting this statistic ceased. During the pandemic (2021) PAS deaths fell slightly, but numbers rose again in 2022. This trend is similar to that seen elsewhere. (7) However it is notable that Oregon PAS deaths remain at a lower prevalence than when euthanasia is also legalized: in 2021 officially notified medically-assisted deaths constituted 4.5% of all deaths in the Netherlands and 3.3% in Canada.

Change in demographics of those accessing PAS

Amongst Oregonians accessing legal PAS, the proportion of people with government health funding (Medicare and Medicaid) has increased relative to those with private health funding. Since 1999, the Oregon OHA reports have not differentiated between Medicare and Medicaid, but only the latter covers the costs of PAS. Medicare is federal insurance for adults ages 65 and older, whereas Medicaid is an insurance option for adults deemed below the poverty line and its availability expanded through the Oregon Health Plan in 2008/9 and 2014. The relative increase in PAS amongst those receiving state funded medical aid changed from 2008 onwards (see graph 1B) but the influence of state funding on uptake can only be analysed with a breakdown of the numbers funded by each system. Unfortunately the destruction of OHA records after one year makes retrospective analysis impossible.

Patients' end-of-life concerns are reported across eight categories, allowing several concerns to be reported. It is unclear whether these are the patients' direct reports or those reported retrospectively by the clinician. Concerns cited about 'losing autonomy' (91%) and 'less able to enjoy activities making life enjoyable' (90%) remain dominant across each year. Over time, there has been an increase in the proportion of patients including concern about being a burden on their caregivers and in those expressing financial concerns about their treatment.

The OHA reports reveal a higher uptake of PAS amongst those with higher educational levels, but income levels are not given. In Belgium, lower education levels are associated with less intense pain and symptom alleviation, but income was not examined.(8) It is possible to have a high education attainment, but be on a low income. Other vulnerabilities are becoming clearer. For example, patients with mental health issues asking for assisted death in the Netherlands were more likely than the general population to be female, single, of lower educational background and with a history of sexual abuse.(9) In Switzerland, although PAS

was associated with higher socio-economic status, PAS was also more common in females and situations indicating vulnerability such as living alone or being divorced.(10) In 2018 an Oregon Health Statistics official acknowledged that they will accept PAS requests if the patient has refused treatment for financial reasons.(11) Although socioeconomic data already exists for some medical conditions in Oregon, (12) these have not been linked to PAS requests.

Recently the cost benefit to individuals and to society of assisted deaths have been discussed in relation to Quality Adjusted Years (QALYs). (12) Economic arguments in support of assisted deaths include the avoidance of possible negative quality of life of the patient, freeing up healthcare resources for others including organs for transplantation. (13) Canada's C-14 Bill has been estimated to provide a net cost saving overall of \$86.9 million in 2021 (gross healthcare cost reduction \$109.2 million less \$22.3 million cost of administering MAiD).(14) A 2019 US Gallup poll found a quarter of respondents reported they or a family member had been put off treatment for a serious medical condition because of the cost.(15) In 2020, 31.6 million people in the US (9.7% of the population) had no medical insurance.(16)

There is a dearth of studies linking socioeconomic vulnerability and PAS data. The change in health funding in Oregon is unlikely to be due to a lag in data since the change to state funding started 15 years ago. Detailed studies are needed to explain the marked change in medical funding for PAS patients in Oregon.

Factors influencing the wish to die

The very low referral rate for psychiatric evaluation could be the result of an efficient screening process. However, there is evidence that depression and existential issues such as hopelessness can influence a wish to die and are commonly missed by doctors.(17, 18) Loneliness is known to be associated with depression which, in turn, increases the likelihood of a wish to die.(19) Elder abuse, which can be difficult to identify, has become a major public health issue in both the US and UK,(20, 21) and in Oregon, elevated rates of non-assisted suicide have been observed in older women.(6, 22) The OHA data shows that the duration of the patient-physician relationship is now almost the same as the time from first request to the assisted death. This steady reduction in the physician-patient relationship in Oregon may have made it more difficult to identify treatable factors influencing the wish to die, but there is a lack of recent data on how many Oregon PAS patients have a treatable depression.

PAS drugs

Until 2014, most prescriptions in Oregon were for secobarbital (54.2%) or phenobarbital (42.8%). US barbiturate availability fell in 2014 as barbiturates were used in state executions and prices rose over 7-fold from 2010 to 2016 (\$387.52 to \$2878.09). (23) Attempts to improve their efficiency in inducing unconsciousness and in time to death resulted in different drug combinations since 2015. Despite some

collation of data by the American Clinicians Academy on Medical Aid in Dying, no research institution has orchestrated studies to evaluate the mode of action and efficacy normally required of clinical processes, with ethical and clinical safeguards for patients.(24, 25)

In 2022, 146 Oregon physicians wrote prescriptions, one of whom wrote 51 prescriptions. These doctors represent less than 0.9% of the 16,621 active medical licensees. (26) There is a lack of data on whether this results in difficulty seeking a prescriber, whether those writing few prescriptions have limited experience of assessing eligibility and what happens to the nearly half of prescribed PAS drugs that are unused.

Oregon does not provide data on what proportion of PAS deaths take a particularly long time to die.

Washington reported that in 2021 31% of patients died within 30 minutes; 16% took more than 2 hours to die. Although the time was unknown in 17.9%, the Washington reports provide no information on the drugs used and whether they were changed to achieve shorter dying times. (27)

The Oregon OHA reports show that complications affect 1 in 9 patients on average, although Oregon does not include prolonged deaths or patients who regained consciousness in their complication percentages. A peak in the complication rate (14.8%) in 2015 coincides with a switch to drug combinations. However, the true incidence of complications is unknown since in 2022 data on complications was missing in 206/278 (74%) of assisted deaths. (1)

Changes in criteria

Oregon is often given as an example of stable assisted dying legislation.(28, 29) In January 2020 Oregon waived the statutory 15-day waiting period for patients estimated to have a shorter prognosis, resulting in a quarter being granted this exemption in 2022.(1) In 2022, 16 patients (6%) outlived their six-month prognosis following prescription of PAS drugs, but there is no detail on how many had treatable conditions or had been misdiagnosed. In 2017 the OHA confirmed that incurable terminal illness is when an affirmative response to the question “*should the disease be allowed to take its course, absent further treatment, is the patient likely to die within six months?*” (11) Any patient has the right to refuse treatment, but it is concerning that there is a lack of data on why they refused treatment and how they were advised and counselled.

For example, in 2021 anorexia nervosa was one of the diagnoses listed, but without any details of co-morbidities, if this was an isolated case or whether the clinician misjudged the prognosis or misapplied the law. Anorexia nervosa in any young adult with capacity is terminal if it persists, but it can be challenging to determine the point at which treatment is futile.

In 2022 a federal lawsuit brought by an Oregon doctor forced Oregon to allow non-residents to access PAS.

Palliative care

In 2022 92% of people requesting PAS were enrolled in hospice and the mean for 1998-2020 was 90.8 %. However, there is no data on what services were provided and the term ‘palliative care’ is not mentioned in any reports, nor the duration of enrollment. Unlike in UK, enrollment in hospice care was described to Lord Mackay’s Select committee as ‘pretty much a one way street’ for ‘comfort only’, as other interventions would no longer be paid for. (30)

In 2012, a study looked at the policies of 56 Oregon hospice programs regarding the state’s PAS legislation; thirty-six hospices (64%) were not directly involved in, or actively opposed to, PAS. (31) Although many of the hospices were willing to have PAS discussions and refer to PAS doctors, 9 (16%) hospices were clear that any involvement violated their policies. In addition, 31(55%) of hospices had policies specifically preventing their staff from being present during the ingestion of PAS drugs. A more recent study interviewed 10 experienced professionals in Oregon, and some stated that hospice organisations continued to be unsupportive of Oregon’s PAS legislation. (32) The lack of information on whether Oregon PAS patients are receiving care from specialist, interdisciplinary palliative care, or a single, non-specialist practitioner, makes it difficult to evaluate whether adequate palliative care was received prior to PAS in Oregon.

Limitations of analysis

We limited our analysis to descriptive trends. Retrospective analyses for PAS in Oregon are limited to the content of published reports since Oregon destroys all source records one year after each annual report, making verification of data impossible. (33) In addition, missing data for some variables (eg. complications) was high and Oregon does not collect data on how or why PAS decisions were made, pre-evaluation or post-mortem review of cases and the details of rejected requests.

We have found no evidence of the completeness or otherwise of the notification process. As there is no prescription monitoring service in Oregon, it is not possible to triangulate data on prescribed lethal drugs, their ingestion and disposal of unused drugs. As physicians are not required to be present when lethal drugs are taken, data provided for the reports depends on information from whoever was present and from provider questionnaires.

CONCLUSIONS

Oregon is often cited as a stable example of assisted dying legislation. Despite Oregon producing detailed and regular post-death reports of value, there are considerable gaps in the data across US States. (34) Most importantly, there is no monitoring in any form of the quality of the consultation in which the decision was made to prescribe lethal drugs. (35) Although population mortality follow-back studies have been used to study end-of-life care, these have limitations.(36) Detailed, prospective studies that include socioeconomic and clinical information are essential to fully understand the changes seen Oregon PAS data.

ACKNOWLEDGEMENT

We acknowledge Professor Katherine Sleeman, Laing Galazka Chair in palliative care at King's College London, who made helpful comments on drafts of this manuscript.

CONFLICT OF INTEREST

None of the authors have a conflict of interest.

FUNDING STATEMENT

None of the authors have received any funding for this research.

CONTRIBUTORSHIP STATEMENT

All three authors conceived and planned the research.

Ana Worthington did the initial collation of data from 1998-2021 and subsequent data analysis, and has contributed since to each draft.

Claud Regnard continued the data analysis, taking responsibility for the text, figures and references, including adding data from the latest OHA report published in early March 2023.

Illora Finlay has reviewed and contributed to each draft throughout the process.

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