

# Pain and Suffering as Reasons for Requesting MAiD in Oregon

By Thad Mirer

Director, [Death with Dignity–Albany](#)

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Since Oregon’s Death with Dignity Act went into effect in late 1997, the state health agency has issued annual reports on activity under the law. These reports include information on why people request a prescription for life-ending medication. The summary findings on this question are frequently cited by friends and foes of the law alike, uncritically, perhaps because the data seem to be authoritative and the best available.

The report for 2023 includes this statement: “As in previous years, the three most frequently reported end-of-life concerns were loss of autonomy (92%), decreasing ability to participate in activities that made life enjoyable (88%), and loss of dignity (64%).” For the last 15 years the reports have included a one-sentence summary of the data on concerns very much like that in 2023.

Opponents of medical aid in dying (MAiD) cite these statements as evidence that pain and suffering are not the reasons people use the law. They say the data show that users are just unhappy with the changes that being old often brings and that this is not a sufficient reason for society to enact MAiD laws.

Friends of MAiD sometimes consider the same reports as indicating a kind of suffering. However, the strongest arguments used by advocates to support the enactment of MAiD in new states have to do with pain that is not sufficiently relieved by hospice and palliative care. The experiences of numerous patients in this situation are compelling, and they highlight the need for a compassionate

option to deal with this. But, one might wonder, why doesn't this pain show up more in the data from Oregon?

[ Pain and suffering do show up more in the data from Canada. Canada's medical-assistance-in-dying program is very different from U.S. MAiD programs, in many ways. Of relevance here is that to be eligible for the program a patient must experience unbearable physical or mental suffering from their illness, disease, disability or state of decline that cannot be relieved under conditions that the patient considers acceptable. Thus data would show that 100% of the persons receiving assistance in dying experience that degree of suffering. In 2022, there were 13,241 MAiD deaths reported, accounting for 4.1% of all deaths in Canada. That's a lot of unbearable pain and suffering. ]

The purpose of this paper is to explain how the Oregon data on why people request a prescription are collected, summarized, and reported. It turns out that the data and reports may not mean what advocates and analysts presume they do. The data collection and reporting serve to downplay the role of a patients' concerns regarding pain and suffering. Thus advocates, analysts, and critics should be very careful in using the data.

### **The Medical-Aid-in-Dying Procedure**

The medical-aid-in-dying procedure in Oregon is similar to that in the nine other jurisdictions with similar laws. People can request a prescription for life-ending medication from a physician when they *qualify* for it, and then they can take the medication if and when they *need* it. About one-third of the people who receive the medication never take it.

People qualify for MAiD if they have a terminal disease with a prognosis of six months or less to live, if they are capable of making an informed decision, and if they are making the request voluntarily. Whether the person has, or fears, pain or suffering is not a factor in determining eligibility.

When a person makes an oral request to their physician for a prescription for lethal medication, they do not need to provide any reasons for their request or to say what their concerns are. Many people don't like to talk about their pain and suffering, or about their fears regarding these. Thus people's reasons for requesting a prescription may not be fully revealed, and no data can show these reasons.

Nonetheless, at the time of the request the physician can listen to whatever the patient says and the physician may ask about the patient's reasons for requesting the medication. As a result, most physicians will form some beliefs about what concerns led to the patient's request. Because of the nature of the information available to the physician, their beliefs are likely to be weak indicators of what the patient's reasons for requesting the medication truly are.

A person also needs to make a written request for the medication, on a form presented in the law. On this form, the patient is not asked to provide any reasons for making the request, and there is no way that the patient could indicate what they might be.

### **Data Collection and Reporting**

Soon after the prescription is written the attending physician submits a compliance form to the Oregon Health Authority, and after the patient dies the physician submits a follow-up form. The compliance form focuses on the procedures followed by the physician up to and including writing the prescription. The follow-up form includes information about the patient and about the death.

In addition, the Health Authority uses data from death certificates and possibly other sources.

In the follow-up form the physician submits after the patient dies, the following question appears:

15. Several possible concerns contributing to the patient's decision to request a prescription for lethal medication are shown below. Please check yes, no, or unknown to indicate whether you believe each concern contributed to the patient's request.

A concern about...	Yes	No	Unk
...the <u>financial cost</u> of treating or prolonging his or her terminal condition?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...the physical or emotional <u>burden on family</u> , friends, or caregivers?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...his or her terminal condition representing a steady <u>loss of autonomy</u> ?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...the decreasing ability to participate in activities that made life <u>enjoyable</u> ?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...the loss of <u>control of bodily functions</u> , such as incontinence and vomiting?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...inadequate <u>pain control</u> at the end of life?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U
...a <u>loss of dignity</u> ?	<input type="checkbox"/> Y	<input type="checkbox"/> N	<input type="checkbox"/> U

To review what is here: The question asks about concerns that the physician believes contributed to the patient's request. The table lists seven concerns that *possibly* (i.e., *might have*) contributed to the patient's decision to request the prescription. Physicians are asked to indicate, for each one separately, whether they believe it *did* contribute to their patient's request. The physician checks an answer: yes, no, or unknown.

Only one listed concern relates to pain, "inadequate pain control at the end of life". This may be just one aspect of a person's concern about pain, and the other aspects do not get reported. There is no way to know whether the physician believes that any of the listed concerns are a source of suffering.

Each Annual Report includes extensive tables of data from the follow-up forms and death certificates, plus verbal summaries of the data. The tables and associated summaries cover only those persons who died from taking the

prescribed medication. For 2023 the data from physicians’ answers to Question 15, about concerns, are given in part of Table 1:

Characteristics	2023	
	(N=367)	
<b>End-of-life concerns<sup>5</sup></b>		
Losing autonomy	336	(91.6)
Less able to engage in activities making life enjoyable	324	(88.3)
<b>Loss of dignity<sup>6</sup></b>	234	(63.8)
Losing control of bodily functions	171	(46.6)
Burden on family, friends/caregivers	159	(43.3)
Inadequate pain control, or concern about it	126	(34.3)
Financial implications of treatment	30	(8.2)

This table includes data for all death-with-dignity deaths during 2023. The first column of data gives the number of cases for which the physician checked YES in the corresponding line of Question 15. In each row, the number in parentheses is the percentage of all cases (N=367) that the number to its left amounts to. The rows are arranged according to the frequency of YES responses, and so the arrangement is different from that in Question 15. (The footnotes do not contain additional relevant information. The Loss of dignity box is highlighted in the online report, but the highlighting seems to have no meaning.)

The first three rows in the table are the source of the Annual Report’s statement about “the three most frequently reported end-of-life concerns”. Since 2010, this has been a very quotable one-sentence summary, in which the concerns about autonomy and about engaging in activities have traded places in the first two ranks. The concern about loss of dignity has ranked third. Physicians reported their belief that a concern about inadequate pain control contributed to

the patient's request in 34% of the cases of death-with-dignity deaths in 2023. In the past 10 years, this percentage has ranged from 21% to 35%.

## **Comments**

Aside from Question 15 in the follow-up form, there is nothing else in the current information collection system that bears on the reasons why the patient requested the prescription or what their concerns were. In the first eight years of operation of the program, before the follow-up form was used, the state health agency conducted telephone interviews with prescribing physicians after a death certificate was filed for the patient. In 1999, interviews were also conducted with family members of patients who died from the prescribed medication. These were more open-ended than the interviews with physicians. With regard to the patient's reasons for requesting the prescription, family members cited physical suffering in more than half the cases, and they raised additional patient concerns not addressed by physician interviews.

It is important to note that no data are collected about the patient from the time the prescription is written until the patient's death. Thus, for those who eventually did take the medication, there is no information about what factors may have precipitated the decision to take it. About one-third of patients who request and receive the lethal medication never take it. Although physicians file the follow-up form for these patients, the annual reports contain no information about these patients' concerns nor any information about why they did not take the medication.

Also, there are deeper questions about studies like this, which are beyond the scope of this paper. For example, people may be concerned that pain will prevent them from engaging in activities that would make their life enjoyable and will

make them appear undignified. Also, caregivers may take over their lives and push them to take pain control medications that cause other problems — the patient may lose autonomy. Thus, fear of pain may be an important factor underlying the top three reasons cited by physicians as being the reasons patients request the medication.

Finally, the Oregon Death with Dignity Act requires the health agency to collect information regarding compliance with the law, and it requires the agency to make available to the public an annual statistical report of this information. Since the reasons why a person seeks the medication are not mentioned in the law, information about these reasons is not related to compliance with it. Data on physicians' concerns and other items are collected as "special studies". In view of this, it is surprising that the annual reports have continued presenting information about concerns based on a conceptual framework and list of possible concerns that are virtually unchanged since the first report. Perhaps our understanding of the role of pain and suffering in persons' decisions to request MAiD would be better served by diverse scientific and academic studies, which can try different approaches and can be compared and discussed critically.

## **Wrapping Up**

How good are the official data and reports about the reasons why users of Oregon's Death with Dignity Law request a prescription for medication to end their lives? Bringing some points together:

- (1) The data underlying the frequently-cited findings are only the physician's beliefs about what the patient's concerns were. These beliefs were formed at the beginning of the process, in a situation where the patient did not have to give any reasons for their request or to express what their concerns were.

These beliefs are reported by physicians only at the end of the process, after the patient dies from taking the prescription.

(2) The only path for the physician to indicate their belief about a patient's concern for pain is through a statement about "inadequate pain control at the end of life".

(3) There is no attempt to assess the extent of suffering that may occur or be feared, other than the statement about inadequate pain control.

(4) No data are collected about the patient from the time the prescription is written until the patient's death.

Thus, reports from Oregon based on the official data do not provide a solid basis for understanding the extent of pain and suffering that users of aid-in-dying fear or experience. They should not be used as though they do.

### **Sources of Information**

A single webpage of the Oregon Health Authority gives current access to all the Annual Reports, all the forms used in the process, and the law:

<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx>

The documents most referred to here are:

*Oregon Death with Dignity Act: 2023 Data Summary*, Oregon Health Authority, <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf> , (esp. pgs. 8, 14).



*Attending Physician Follow-up Form, Oregon Health Authority,*  
<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/mdintdat.pdf>

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