CONCERNS LEADING TO REQUESTS FOR LETHAL MEDICATION UNDER OREGON'S ASSISTED SUICIDE LAW

What do attending physicians who prescribe lethal medication under Oregon's Death With Dignity Act know or believe are the concerns contributing to the decision of those who have subsequently died following ingestion of the lethal medication?

A report by Richard Egan

Data on this question is published annually by the Oregon Health Authority. The latest report is for 2018.

The data is derived from Question 15 in Part B of the "Oregon Death with Dignity Act Attending Physician Follow-up Form"

On 5 March 2019 I queried by email to the Oregon Health Authority the percentages given in Table 1 of the 2018 Data Summary under End of Life Concerns as they did not seem to be correct .

For example for 2018, if N=168 then the correct percentage for "Losing autonomy (%) " if N=168 and the number was 154 should have been 91.7% rather than 95.1% as given.

In an email reply dated 8 March 2019 Craig New, Research Analyst, Oregon Health Authority explained:

"*The discrepancy is because we exclude unknown values from the denominator when calculating percentages. So, for example, 154 patients had "losing autonomy" as a reason for seeking DWDA in 2018, but six patients were reported as "unknown" on this reason. 154 / (168-6) = 95.1%*"

I applied this information to the data on "End of Life Concerns" for 2018 and for the total data 1998-2018) and produced the table below.

What is immediately striking is the lack of knowledge attending physicians admit to having about some of the concerns that may have contributed to a person requesting a prescription for lethal medication.

A lack of knowledge by the attending physician of whether or not a particular concern contributed to a request for a prescription for lethal medication necessarily implies either that the attending physician NEVER explored that possible concern with the person or, if the attending physician did attempt to explore that possible concern he or she did not success in eliciting a sufficient response from the person to form a view as to whether or not the person had that possible concern.

Steady loss of autonomy and decreasing ability to participate in activities that made life enjoyable

These concerns clearly dominate the discussion between attending physicians and persons requesting a prescription for lethal medication. Only in around 1 in 20 cases does the

attending physician admit to not knowing is these were concerns contributing to the request.

Loss of dignity

In about one out of six cases the attending physician reports not knowing if loss of dignity was a concern for the person.

Burden on family, friends or caregivers

In 2018 in 14.9% of cases (nearly one in seven cases) the attending physician reported not knowing if the person who requested lethal medication and subsequently died after ingesting had a concern about physical or emotional burden on family, friends or caregivers.

ORS 127.815 sets out as the very first responsibility of an attending physician under the Death With Dignity Act a duty to "*Make the initial determination of whether a patient has a terminal disease, is capable, and has made the request voluntarily*"

How can a physician come to a firm conclusion that a person is voluntarily requesting lethal medication in order to end their lives without exploring whether or not the person is motivated by a concern about the physical or emotional burden on family, friends or caregivers?

Surely such a discussion is necessary to exclude any possibility that the person is making the request under duress, subject to coercion or undue influence from a family member or caregiver.

Additionally, in the absence of such a discussion there may be a missed opportunity to relieve the person's concern about being a burden by arranging respite for family caregivers or additional care or support.

If the 14.9% of cases where the attending physician does not even bother exploring this issue with a person before writing a prescription for lethal medication are added to the 54.2% of cases in 2018 where the attending physician reports knowing that the person had a concern about the physical or emotional burden on family, friends or caregivers then in nearly seven out of ten cases (69.1%) concern about being a burden are or maybe a factor in a request for lethal medication.

Given what we know about elder abuse this is cause for alarm.

Inadequate pain control at the end of life

In 2018 in 17.9% of cases (nearly one in six) the attending physician reports that he or she does not know whether or not the person who has died after ingesting lethal medication which the physician prescribed had any concern about inadequate pain control at the end of life.

ORS 127.815 sets out as another of the responsibilities of an attending physician under the Death With Dignity Act a duty "*To ensure that the patient is making an informed decision,*

inform the patient of the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control".

Before lethal medication is prescribed a person must sign a request form affirming, among other things, "*I have been fully informed of my diagnosis, prognosis, the nature of medication to be prescribed and potential associated risks, the expected result, and the feasible alternatives, including comfort care, hospice care and pain control*."

But if the attending physician has not asked the person about any concerns about inadequate pain control at the end of life how can the attending physician possibly have properly informed the person about feasible alternatives to ingesting lethal medication such as "comfort care, hospice care and pain control"?

Loss of control of bodily functions, such as incontinence and vomiting

In over one in five cases (20.2%) in 2018 the attending physician reports not knowing whether or not the person had any concern about the loss of control of bodily functions, such as incontinence and vomiting.

Of course in many cases these concerns can be alleviated. There are many methods for treating or managing incontinence or vomiting. Simply discussing the concern with a listening, compassionate physician may be sufficient to relieve it, at least to the point where it is not a reason to request lethal medication.

The financial cost of treating or prolonging his or her terminal condition

In more than one out of four cases (26.8%) in 2018 the attending physician simply did not bother to find out whether or not a concern about the cost of treatment or care was underlying the request for lethal medication.

How can an attending physician form a valid view that a request for lethal medication is being made "voluntarily" if a possible concern about the financial costs of treatment or care is never explored with the person?

In some cases treatments may be available that are effective and could either cure the person from the terminal condition or significantly extend their life with good quality. If the person is forgoing such treatments because of a concern about the cost which is not even discussed with the attending physician isn't that a tragedy and a failure of the care due from a physician to a patient?

The attending physician is obliged by ORS 127.815 "*To ensure that the patient is making an informed decision, inform the patient of the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control*".

If the person has a concern about the cost of "comfort care, hospice care and pain control" that is not disclosed to the attending physician because he or she never bothers to ask then how can a decision by the person to request lethal medication instead of "comfort care, hospice care and pain control" possibly be fully informed and voluntary?

Conclusion

Thanks to the explanation from Mr New of the Oregon Health Authority we are now better placed to interpret the data from Oregon on the concerns people requesting lethal medication discuss with attending physicians and the concerns that may motivate such requests but are simply not explored by attending physicians or at least not explored sufficiently for the attending physician to form a view as to whether or not such a concern was contributing to the person's request for lethal medication.

In more than **one in four cases** there is no discussion of concerns about the **financial cost of** treating or prolonging his or her terminal condition.

In more than **one in five cases** there is no discussion of concerns about the loss of control of bodily functions, such as **incontinence and vomiting**.

In nearly **one in six cases** there is no discussion of concerns about **inadequate pain control** at the end of life.

In nearly **one in seven cases** there is no discussion of concerns about being a physical or emotional burden on family, friends or caregivers.

This suggest that in many cases discussions between attending physicians and persons requesting lethal medication are almost solely around autonomy and related matters and that there is no serious discussion about underlying issues such as family dynamics, feelings of being a burden, financial considerations, pain control or loss of bodily functions at the end of life.

In the absence of such discussions it seems that an attending physician could not have properly fulfilled the obligation under the Death With Dignity Act to have fully informed the person of feasible alternatives.

Nor could the physician come to a genuine conclusion that the person was making a fully informed and truly voluntary decision to request lethal medication.

Table 1: Concerns contributing to request for lethal medication in Oregon for 2018 and for 1998-2018

Question 15 in Part B of the "Oregon Death with Dignity Act Attending Physician Follow-up Form" reads:

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.

The results derived from data published in the 2018 Data Summary are as follows:

A CONCERN ABOUT …	2018 YES	2018 NO	2018 UNKNOWN	TOTAL YES	TOTAL NO	TOTAL UNKNOWN
the financial cost of treating or prolonging his or her terminal condition?	5.4%	67.9%	26.8%	3.9%	79.2%	16.9%
the physical or emotional burden on family, friends, or caregivers?	54.2%	31.0%	14.9%	44.8%	41.5%	13.6%
his or her terminal condition representing a steady loss of autonomy?	91.7%	4.8%	3.6%	90.6%	4.2%	5.1%
the decreasing ability to participate in activities that made life enjoyable?	90.5%	4.2%	5.4%	89.1%	5.1%	5.8%
the loss of control of bodily functions, such as incontinence and vomiting?	36.9%	42.9%	20.2%	44.3%	34.1%	21.5%
inadequate pain control at the end of life?	25.6%	56.5%	17.9%	25.7%	60.5%	13.8%
a loss of dignity?	66.7%	17.3%	16.1%	74.5%	10.7%	14.8%