Reasons for requesting medical assistance in dying

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Editor's key points

- Canadians have had the right to medical assistance in dying (MAID) since June 2016. This study aimed to examine the reasons patients in British Columbia gave for requesting MAID, both those who received MAID and those who did not, in the first 6 months of the new law.

- The reasons these patients gave for requesting assisted deaths included loss of autonomy, loss of ability to do enjoyable or meaningful activities, disease-related symptoms, and fear of future suffering. There was a higher proportion of people who gave disease-related symptoms as their reason than reported in other studies, as well as a higher proportion of patients with neurological disease and end-organ failure.

- People who had received formal palliative care were more likely to say that symptoms were their most important reason for the request than those who had not received palliative care were, and those who requested and were eligible for but did not have an assisted death during the study period were more likely to cite fear of future suffering as their reason for the request than those who received MAID were.

Abstract

Objective To review the charts of people who requested medical assistance in dying (MAID) to examine their reasons for the request.

Design Retrospective chart survey.

Setting British Columbia.

Participants Patients who requested an assisted death and were assessed by 1 of 6 physicians in British Columbia during 2016.

Main outcome measures Patients' diagnoses and reasons for requesting MAID.

Results Data were collected from 250 assessments for MAID: 112 of the patients had assisted deaths, 11 had natural deaths, 35 were assessed as not eligible for MAID, and most of the rest were not ready. For people who had assisted deaths, disease-related symptoms were given as the first or second most important reason for requesting assisted death by 67 people (59.8%), while 59 (52.7%) gave loss of autonomy, 55 (49.1%) gave loss of ability to enjoy activities, and 27 (24.1%) gave fear of future suffering. People who were assessed as eligible but who had not received assisted deaths were more likely to list fear of future suffering (33.7% vs 7.1%) and less likely to list disease-related symptoms (17.4% vs 40.2%) than those who received MAID were. There was a difference in reasons for MAID given by people with different diagnoses; disease-related symptoms were given as the most important reason by 39.0% of patients with malignancies, 6.8% of patients with neurological diseases, and 28.9% of patients with end-organ failure. Loss of autonomy was given as the most important reason by 16.0% of patients with malignancies, 36.4% of patients with neurological diseases, and 23.7% of patients with end-organ failure.

Conclusion This study shows that the reasons patients give for requesting an assisted death are similar to those reported in other jurisdictions with similar laws, but in different proportions. Loss of autonomy and loss of ability to enjoy activities were less common reasons among patients in this study compared with other jurisdictions. This might be related to the method of data collection, as in this study, the patients' reasons were recorded by physicians.

Les raisons pour demander l'aide médicale à mourir

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Résumé

Objectif Vérifier les dossiers de personnes qui ont demandé l'aide médicale à mourir (AMM) pour connaître les raisons qu'ils ont données pour le faire.

Type d'étude Une revue rétrospective de dossiers.

Contexte La Colombie-Britannique.

Participants Des patients qui ont demandé l'AMM et qui ont été évalués par l'un de six médecins de Colombie-Britannique durant l'année 2016.

Principaux paramètres à l'étude Les diagnostics des patients et les raisons pour lesquelles ils demandaient l'AMM.

Résultats Il y a eu 250 cas pour lesquels on a pu évaluer la raison de la demande d'AMM : de ce nombre, 112 avaient reçu ce type d'aide, 11 étaient décédés de mort naturelle, 35 ont été jugés non admissibles à l'AMM et la plupart des autres disaient ne pas être prêts à faire cette demande. Pour 67 sujets (59,8 %) qui avaient reçu cette aide, les premières ou deuxièmes raisons en importance pour demander l'AMM étaient les symptômes liés à leur maladie, tandis que pour 59 autres (52,7 %), c'était la perte d'autonomie, pour 55 (49,1 %), l'incapacité de pratiquer des activités agréables et pour 27 (24,1 %), la crainte des souffrances à venir. Les personnes qui avaient été jugées admissibles mais n'avaient pas reçu l'AMM étaient plus susceptibles que celles qui l'avaient reçue de donner comme raison la crainte des souffrances futures (33,7 % c. 7,1 %) et moins susceptibles d'invoquer les symptômes liés à leur maladie (17,4 % c. 40,2 %). Les raisons pour demander l'AMM différaient selon les diagnostics : pour 39,0 % des cancéreux, 6,8 % de ceux qui avaient un problème neurologique et 28,9 % de ceux qui présentaient la défaillance d'un organe, la principale raison de leur demande était les symptômes causés par leur maladie. Pour 16,0 % des cancéreux, 36,4 % de ceux avec un problème neurologique et 23,7 % de ceux qui présentaient une défaillance d'un organe, la principale raison invoquée était la perte d'autonomie.

Conclusion Cette étude montre que les raisons invoquées par les patients pour demander l'AMM ressemblent à ce qui a été observé dans d'autres juridictions qui possèdent des lois semblables, mais dans des proportions différentes. Par rapport aux autres juridictions, la perte d'autonomie et l'incapacité de pratiquer des activités agréables étaient des raisons moins fréquentes dans la présente étude. Cela pourrait dépendre de la méthode utilisée pour recueillir les données, car dans cette étude, ce sont des médecins qui ont enregistré les raisons.

Points de repère du rédacteur

- C'est depuis juin 2016 que les Canadiens ont le droit à l'aide médicale à mourir (AMM). Cette étude voulait vérifier les raisons invoquées par des patients de Colombie-Britannique pour demander cette aide, et ce, qu'ils aient ou non reçu cette aide au cours des 6 mois suivant la promulgation de cette loi.

- Parmi les raisons invoquées pour demander l'AMM, mentionnons la perte d'autonomie, la perte de capacité à entreprendre des activités agréables ou importantes, la présence de symptômes causés par leur maladie et la crainte des souffrances à venir. Par rapport à d'autres études, la proportion de personnes qui donnaient comme raison la présence de symptômes liés à la maladie était plus élevée et il y avait aussi plus de sujets souffrant d'un problème neurologique ou présentant une défaillance d'un organe.

- Par rapport aux patients qui n'avaient pas reçu de soins palliatifs, ceux qui en avaient reçus étaient plus susceptibles de dire que leurs symptômes étaient la principale raison pour demander l'AMM; par ailleurs, ceux qui étaient admissibles à cette assistance et qui l'avaient demandée sans en avoir profité durant la période de l'étude étaient plus susceptibles que ceux qui avaient reçu cette aide de dire que la peur des souffrances à venir était la raison de leur demande.

Canadians have had the right to a medically assisted death since the Carter decision came into effect on February 6, 2016, and the medical assistance in dying (MAID) law was passed on June 17, 2016.[1] People are eligible for a medically assisted death if they are older than 18 years of age, are eligible for publicly funded Canadian health care, and have a grievous and irremediable condition that causes them suffering, and if their natural death is in the foreseeable future. The law allows for the medications to be self-administered or administered by a physician or nurse practitioner. The provincial colleges that license physicians published guidelines for the practice of MAID that include submitting forms from the patient requesting MAID and from 2 physicians or nurse practitioners who agree that the person has met the criteria.[2] The MAID forms are submitted to the provincial agency providing oversight (usually provincial coroners' offices). These forms provide information about why someone met the criteria for MAID but not what his or her reasons were for requesting MAID. There is no information on those who are deemed ineligible or who die natural deaths. Therefore, the only feasible way to get this information is a retrospective chart survey from some of the practitioners who assess people for MAID.

Current literature about requests for assisted deaths and reasons why patients request assisted deaths come from studies in jurisdictions that have much more experience than Canada has. Laws in the Netherlands, similar to Canadian law, have allowed both doctor-administered and self-administered assisted deaths since 2002. A 2013 report from the Netherlands stated that the most common diagnoses in assisted deaths were cancer (74.3%), neurological disorders (6.1%), multiple geriatric syndromes (5.2%), and cardiovascular disease alone (4.6%).[3] Since 1997, the state of Oregon has had a Dying with Dignity law allowing self-administered assisted deaths. In Oregon, most patients receiving prescriptions for self-administered assisted deaths had cancer: 68.6% in 2014 and an average of 79.4% between 1997 and 2013.[4] Not everyone who requests an assisted death actually has one; only 859 of 1327 (64.7%) lethal prescriptions written between 1997 and 2014 in Oregon resulted in patient death. In 2014 in Oregon, most (89.5%) patients died at home and most (93.0%) were enrolled in hospice care either at the time the Dying with Dignity prescription was written or at the time of death. In 2014, as in previous years, the 3 most frequently mentioned end-of-life concerns were loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%).[4]

In Canada, MAID is a new area of medical practice. We need to know not only about diagnoses but also about reasons for requests and about unfulfilled requests. This will provide the best possible information and care for our patients.

Methods

This was a retrospective chart survey of patients who requested an assisted death and were assessed by 1 of 6 physicians in British Columbia who had been accepting referrals since the law changed. Clinical charts have additional information compared with the MAID forms that are submitted to the coroner's office. The charts included patients who did not have assisted deaths but who died naturally after the request, patients who were eligible but who were still waiting for the right time, and patients who were not eligible. The charted notes of interviews also had insight into the reasons patients sought an assisted death in addition to the diagnosis or diagnoses that made them eligible for MAID.

A research assistant (M.K.) reviewed the charts of all patients assessed for MAID between February 6 and December 17, 2016. This was done with each physician to aid in interpretation of the charting. Any patient assessed within the period who had an assisted death after December 17, 2016, was coded as not having received MAID. We recorded demographic characteristics such as age and sex, diagnoses, reasons for the request, and whether the patient was considered eligible for MAID. We also recorded the timeline of when the assessment occurred and when and how the death occurred.

This project was approved by the University of British Columbia Research Ethics Board.

Results

We collected data on 250 assessments for MAID: 112 assisted deaths, 11 natural deaths, 35 found not to be eligible, and 92 others (**Table 1**). Four doctors provided data on all the assessments they had done, while 2 provided data only for those who had assisted deaths. Fifty-six (22.4%) of the assessments were done at least partly by telehealth. Five assisted deaths occurred between February 6 and June 6, 2016, when the Carter decision was in effect and each patient required a judge to approve the request; 2 assisted deaths occurred between June 6 and June 17, 2016, when the Carter decision was in effect but no judicial approval was required. The rest (105) occurred between June 17 and Dec 17, 2016, the first 6 months after the MAID law was passed.

The patients who had assisted deaths ranged in age from 42 to 102 years with a mean age of 74.1 years; 51 (45.5%) were male and 107 (95.5%) were white. The most common diagnoses were malignancies (n=48, 42.9%). There were 27 (24.1%) patients with end-organ failure (mostly heart failure and lung disease). Neurological diseases were the next most common diagnoses with 25 (22.3%) cases; 9 of those were motor neuron diseases such as amyotrophic lateral sclerosis. Other reported diseases included 4 people with "extreme frailty" who had an average age of 92.3 years.

Of the 138 people who had assessments but did not have an assisted death, 11 died before they could receive MAID, 35 were assessed to be not eligible for MAID, and most of the rest were not ready or just wanted the option to be available later. We used the 2 most important reasons for requesting MAID in the descriptive analysis to give a fuller picture (**Tables 2** and **3**). For people who had assisted deaths, disease-related symptoms were given as the first or second most important reason for requesting assisted death by 67 people (59.8%), while 59 (52.7%) gave loss of autonomy, 55 (49.1%) gave loss of ability to enjoy activities, and 27 (24.1%) gave fear of future suffering (**Table 2**). **Table 3** shows the first and second most important reasons for requesting MAID by diagnosis in the people who had assisted deaths. Of the 35 people who were assessed as not eligible, 18 were refused because their natural deaths were not deemed to be in the foreseeable future, 8 were considered to have primarily psychiatric causes, 7 were assessed as not capable of making health care decisions, and 2 were not considered to be suffering.

When we compared the people who were assessed and eligible for MAID and either did have or did not have MAID, we used the most important reason rather than 2 reasons (for ease of analysis). People who had MAID deaths were more likely to list disease-related symptoms as the most important reason (45 of 112 [40.2%] vs 16 of 92 [17.4%]), while those who were only assessed and had not received assisted deaths were more likely to list fear of future suffering first (31 of 92 [33.7%] vs 8 of 112 [7.1%]). The 69 people who had received formal palliative care were more likely to say that symptoms were their most important reason for the request (69.6% vs 41.2%). There was a difference in reasons given by people with different diagnoses. Among patients who had assisted deaths or who were assessed but did not receive MAID (but excluding patients who were not eligible or who had natural deaths), disease-related symptoms were

Table 1. Primary diagnoses related to medical assistance in dying requests: *N* = 250.

PRIMARY DIAGNOSES	ASSISTED DEATH (N=112), N (%)	ASSESSMENT ONLY (N=92), N (%)	NATURAL DEATH (N=11), N (%)	NOT ELIGIBLE (N=35), N (%)
Malignancy	48 (42.9)	52 (56.5)	7 (63.6)	9 (25.7)
Neurological disease	25 (22.3)	19 (20.7)	2 (18.2)	4 (11.4)
End-organ failure	27 (24.1)	11 (12.0)	1 (9.1)	2 (5.7)
Other	12 (10.7)	10 (10.9)	1 (9.1)	20 (57.1)

Table 2. First and second most important reasons for the request for assisted death: *N = 250; 6 charts had no reasons, 56 had only 1 reason, and some gave 3 or 4 reasons, but only the first 2 reasons were coded.*

REASONS	ASSISTED DEATH (N=112), N (%)	ASSESSMENT ONLY (N=92), N (%)	NATURAL DEATH (N=11), N (%)	NOT ELIGIBLE (N=35), N (%)
Loss of control and independence	59 (52.7)	34 (37.0)	1 (9.1)	12 (34.3)
Loss of ability to do enjoyable and meaningful activities	55 (49.1)	35 (38.0)	2 (18.2)	10 (28.6)
Illness-related suffering (pain, nausea, etc)	67 (59.8)	34 (37.0)	4 (36.4)	23 (65.7)
Fear of future suffering	27 (24.1)	50 (54.3)	2 (18.2)	11 (31.4)
Previous negative experience around death and dying	4 (3.6)	1 (1.1)	0 (0.0)	1 (2.9)

Table 3. First and second most important reasons for request by diagnosis in patients with completed assisted deaths: *N = 112; 12 charts had only 1 reason.*

REASONS	MALIGNANCY (N=48), N (%)	NEUROLOGICAL DISEASE (N=25), N (%)	END-ORGAN FAILURE (N=27), N (%)	OTHER (N=12), N (%)	TOTAL (N=112), N (%)
Loss of control and independence	25 (52.1)	14 (56.0)	13 (48.1)	7 (58.3)	59 (52.7)
Loss of ability to do enjoyable and meaningful activities	21 (43.8)	16 (64.0)	14 (51.9)	4 (33.3)	55 (49.1)
Illness-related suffering (pain, nausea, etc)	35 (72.9)	7 (28.0)	15 (55.6)	10 (83.3)	67 (59.8)
Fear of future suffering	11 (22.9)	9 (36.0)	6 (22.2)	1 (8.3)	27 (24.1)
Previous negative experience around death and dying	1 (2.1)	1 (4.0)	1 (3.7)	1 (8.3)	4 (3.6)

given as the most important reason by 39 of 100 (39.0%) patients with malignancies, 3 of 44 (6.8%) patients with neurological diseases, and 11 of 38 (28.9%) patients with end-organ failure; loss of autonomy was given as the most important reason by 16 of 100 (16.0%) patients with malignancies, 16 of 44 (36.4%) patients with neurological diseases, and 9 of 38 (23.7%) patients with end-organ failure. Those with malignancy were also older than those with neurological disease were (mean age of 73.1 vs 64.3 years).

Discussion

This study shows that the reasons patients gave for requesting an assisted death in British Columbia were somewhat different than those from other jurisdictions. Of the 112 people who had assisted deaths, only 52.7% listed loss of autonomy as 1 of the top 2 reasons for the request; among patients in Oregon it was the most common reason (91.4%).[4] Loss of ability to enjoy activities was given as 1 of the 2 reasons in 49.1% of our patients who had assisted deaths compared with 86.7% of the Oregon patients. Disease-related symptoms were the most common reason given in our study (59.8%). The basic components of suffering were the same as described in a qualitative study of patients in the Netherlands:

> medical, psycho-emotional, socio-environmental and existential … especially fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living.[5]

The reasons given in our study are also similar in quality to those described by relatives of patients who died of euthanasia in the Netherlands.[6] A qualitative study of patients' experiences in Canada indicated that autonomy and quality of life were the most important reasons for a request.[7] The differences between the findings in this study and the others might relate to how the data were collected. In this study, we relied on the way the doctor charted the reasons, while the other studies used forms or asked the patients or relatives directly. The doctors might have been more focused on medical symptoms than existential ones. Also, the doctors needed to justify that the patients were eligible for MAID in their charting.

Although malignancy was the most common primary diagnosis among the patients who had assisted deaths in this group, it was only 42.9% of patients, compared with Oregon's 68.6% and the Netherlands' 74.4%.[3,4] It is possible that since this was the first 6 months of the new law, more patients with neurological diseases and end-organ failure had been waiting for the new legislation. Prognoses can be more predictable in malignancy, which might be the reason for the higher percentage in Oregon, where a 6-month prognosis is required to be eligible.

Of the people who had MAID, those with malignancy were more troubled by disease-related symptoms (39.0% gave this as the most important reason) than those with neurological disease (6.8%) were. Although many people with multiple sclerosis and amyotrophic lateral sclerosis have muscle pains, the main problems they have are related to loss of function. In this study, those with malignancy were also older than those with neurological disease and might also have been less troubled by lack of function.

The patients who received formal palliative care were more likely to list disease-related symptoms as the reason for the request. It is not likely that this is owing to failure of palliative care to address their symptoms. Instead this is probably because patients with loss of function as their main complaint would be referred to palliative care less often.

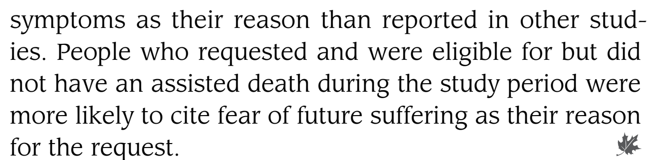
Limitations

This study is limited to those patients who were assessed by a group of 6 physicians in 1 province and only in the first 6 months of the new law. It is possible that other areas of Canada will have different findings and that there will be changes in the next few years as Canadians have more experience with assisted deaths. It would not be possible to capture all the discussions patients had with their own physicians about assisted death, but we were able to record the ones who had formal assessments by this group of physicians. This study is also limited in that its retrospective nature does not allow for patients to cite the order of the reasons they sought MAID. The interview and evaluation that physicians provide in order to assess eligibility differs in style and focus. Therefore, the order in which a doctor reported a patient's reasons for requesting MAID might not match the patient's own rankings of those reasons. It might not identify clearly which component of suffering was rated most highly as a reason to seek MAID at the time of the request. It is also interesting to think of where the requests arise from. For instance, within the hospital and acute care setting, patients might be more provoked by disease-related symptoms, as this is most often what precipitates the admission to hospital and hospice.

The people who had assessments and were eligible included patients who intended to receive MAID but did not do so before the cutoff date, as well as people who were not ready.

Conclusion

The reasons these patients gave for requesting assisted deaths included loss of autonomy, loss of ability to do enjoyable or meaningful activities, disease-related symptoms, and fear of future suffering. There was a higher proportion of people who gave disease-related



symptoms as their reason than reported in other studies. People who requested and were eligible for but did not have an assisted death during the study period were more likely to cite fear of future suffering as their reason for the request.

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Contributors

Drs Wiebe, **Shaw**, and **Green** were involved in the initial design; all authors contributed to preparing the protocol and manuscript and to interpretation of data; **Drs Trouton**, **Green**, and **Wiebe** were providing physicians; and **Ms Kelly** managed the data.

Competing interests

None declared

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