



Editor's key points

► With the legalization of medical assistance in dying (MAID) in Canada, many physicians will be approached for the first time by a patient inquiring about MAID, and many Canadians will have a first experience with a family member or friend who pursues MAID. The results of this study were intended to facilitate a deeper understanding of the unique perspectives and experiences of people who pursue MAID and to provide some insight into their variable preferences for the social and physical environment for MAID to help inform decision making for physicians and governments regarding MAID provision.

► The most prominent theme was that people believed it was important to have autonomy and control over their own lives. They wanted to decide for themselves when their suffering was too great and they wanted to have end-of-life options that included MAID.

► Preferences for the location of death varied and included at home, in a hotel, in a clinic, or in a hospital. Of those who had MAID during the study period, half died at home and half died in a clinic or hospital setting. Some people preferred to be alone for their death or to have only a close loved one present, while others wanted many loved ones to be at their bedside and some form of ceremony such as dinner or exchanging of final words.

Experiences and perspectives of people who pursued medical assistance in dying

Qualitative study in Vancouver, BC

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Abstract

Objective To explore the experiences, wishes, fears, and beliefs of people who requested and were eligible for medical assistance in dying (MAID) in Canada in the first year after legalization.

Design Qualitative study using semistructured interviews.

Setting A clinic in Vancouver, BC, that provides MAID.

Participants People requesting and eligible for MAID between February 6 and December 17, 2016. Family and friends who were identified as the patients' primary support people were also interviewed.

Methods Semistructured interviews were conducted over the telephone, by e-mail, or in person. The interviews were audiorecorded and transcribed and then analyzed using thematic qualitative analysis. The investigators read the transcripts and created a coding scheme to identify themes in the patients' experiences. The identified themes were compiled and evaluated in the context of what is already known based on current literature. Basic demographic characteristics were recorded for context.

Main findings Of the 23 patients whose experiences were explored, most had a malignancy, a neurologic disorder, or organ failure. A main theme was that patients thought it was important to have autonomy and control over their own end-of-life decisions. Main reasons for requesting MAID were a self-perceived unacceptable quality of life, most commonly owing to loss of independence, mobility, ability to communicate, a sense of purpose, and participation in meaningful activity. Some people expressed fear of future suffering and future disability. Pain was seldom mentioned as a cause of suffering. Some participants believed they could discuss their decision with the people in their lives while others chose to keep it a private matter. Most people were not religious.

Conclusion The participants' reasons for choosing to pursue MAID were consistent with those of people in other jurisdictions that have been studied. They felt confident in their decision to pursue MAID and did not have fears about the process.



Expériences et points de vue de personnes ayant demandé l'aide médicale à mourir

Une étude qualitative à Vancouver, Colombie-Britannique.

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Résumé

Objectif Étudier les expériences, les souhaits, les craintes et les croyances de personnes admissibles ayant demandé l'aide médicale à mourir (AMM) au Canada durant la première année suivant la légalisation.

Type d'étude Une étude qualitative à l'aide d'entrevues semi-structurées.

Contexte Une clinique de Vancouver, en Colombie-Britannique, qui offre l'AMM.

Participants Les personnes admissibles à l'AMM et qui l'ont demandée entre le 6 février et le 17 décembre 2016. On a aussi interviewé des membres des familles et des amis considérés comme les aidants principaux.

Méthodes On a effectué des entrevues au téléphone, par courrier électronique ou en personne. Les entrevues ont été enregistrées sur ruban magnétique, transcrites et analysées au moyen d'une analyse thématique qualitative. Après avoir lu les transcrits, les chercheurs ont créé un mode de codage pour identifier des thèmes parmi les expériences des patients. Les thèmes identifiés ont été catalogués et évalués sur la base de ce que l'on connaît déjà d'après la littérature actuelle. On a également enregistré les caractéristiques démographiques de base comme contexte.

Principales observations La plupart des 23 patients qui nous ont fait part de leurs expériences souffraient d'un cancer, d'une maladie neurologique ou de la défaillance d'un organe. Un thème majeur était l'idée qu'avaient les patients qu'il importait d'être autonome et d'avoir le contrôle de ses propres décisions de fin de vie. Les principales raisons pour demander l'AMM étaient l'impression de n'avoir plus de qualité de vie, le plus souvent en raison d'une perte d'indépendance, de mobilité, de capacités à communiquer, d'un but à poursuivre et de la possibilité de participer à une activité significative. Certains disaient craindre les souffrances et l'incapacité à venir. La douleur était rarement mentionnée comme une cause de souffrance. Certains participants croyaient pouvoir discuter de leur décision avec leurs proches, tandis que d'autres préféraient la garder personnelle. La plupart ne pratiquaient pas de religion.

Conclusion Les raisons données par les participants pour choisir de demander l'AMM étaient semblables à celles observées chez des patients d'autres juridictions ayant fait l'objet d'une étude. Ils se disaient confiants d'avoir pris la bonne décision en demandant l'AMM et n'avaient pas de craintes quant au processus.

Points de repère du rédacteur

► Avec la légalisation de l'aide médicale à mourir (AMM) au Canada, beaucoup de médecins seront questionnés pour la première fois à ce sujet par un patient, et de nombreux Canadiens vivront une première expérience où un membre de leur famille ou un ami sollicitera l'AMM. Cette étude avait pour but de mieux comprendre les expériences et les points de vue des personnes qui demandent l'AMM afin de déterminer ce qu'ils souhaiteraient avoir comme environnement social et physique au moment de mourir, mais aussi pour aider les médecins à prendre une décision appropriée et les gouvernements, à bien encadrer l'AMM.

► Le thème le plus récurrent était que les personnes croyaient qu'il importait d'être autonome et d'avoir le contrôle de sa propre vie. Elles voulaient être en mesure de décider elles-mêmes du moment où leurs souffrances seraient intolérables et pouvoir compter sur des choix en matière de fin de vie, dont l'AMM.

► Les préférences quant aux endroits où mourir variaient entre la maison, un hôtel, une clinique ou un hôpital. La moitié des personnes ayant bénéficié de l'AMM durant la période de l'étude sont mortes à domicile et l'autre moitié, dans une clinique ou un hôpital. Certaines personnes voulaient être seules au moment de mourir ou être accompagnées d'une personne très proche, tandis que d'autres voulaient avoir plusieurs proches à leur chevet et une sorte de cérémonie, comme un repas ou un échange de dernières paroles.

In the precedent-setting *Carter v Canada* case, the Supreme Court of Canada held that criminal laws that prohibited medical assistance in dying (MAID) violated the right to “liberty of the person” by preventing people with grievous and incurable medical conditions from making decisions about their own bodily integrity.¹ Following this ruling, a new law permitting MAID was passed on June 17, 2016.^{2,3} Between February 6 and June 6, 2016, MAID was allowed only with court orders.

The term *medical assistance in dying* includes both physician-assisted suicide (a patient self-administers a prescribed lethal medication) and voluntary euthanasia (a medical practitioner administers a lethal medication), both of which are now legal in Canada.^{3,4} Patients must be competent to make medical decisions, must be 18 years of age or older, and must have a grievous and irremediable medical condition that causes them enduring and intolerable suffering and for which natural death is reasonably foreseeable.³

Physician-assisted suicide is legal in Switzerland and in 7 states and the District of Columbia in the United States, while both physician-assisted suicide and voluntary euthanasia are legal in the Netherlands, Belgium, Luxembourg, and Columbia.⁵ The laws vary with respect to the minimum age of eligibility, whether patients must be mentally competent, and whether they must be terminally ill.⁶ A recent review of the literature on practices of euthanasia and physician-assisted suicide in these jurisdictions revealed that 0.3% to 4.6% of all deaths in these jurisdictions are reported as euthanasia or physician-assisted suicide.⁵ Patients were more likely to be older, white, and well educated.⁵ Pain mostly was not reported as the primary motivation, and more than 70% of patients had a diagnosis of cancer.⁵

In the Netherlands in 2013, the most common diagnoses of people who requested MAID were cancer (74.3%), neurologic disorders (6.1%), multiple geriatric syndromes (5.2%), and cardiovascular disease alone (4.6%).⁷ In Oregon, Washington, and Belgium, approximately 70% to 80% of people who requested MAID had cancer.⁸⁻¹⁰

Studies in other jurisdictions have explored the perspectives of people who requested MAID. Dees et al sought to establish a definition of *unbearable suffering* in the context of MAID by performing an integrative literature review.¹¹ They later explored the elements of unbearable suffering through interviews with people in the Netherlands who had requested MAID.¹² They found a multitude of factors that led people to pursue MAID, which included functional impairment, dependency, hopelessness, indignity, intellectual deterioration, loss of oneself, loss of autonomy, fear of future suffering, loss of all that makes life worth living, being a burden, fatigue, and pain.^{11,12} Another Dutch study used retrospective interviews with relatives of people who had MAID.¹³ The relatives shared that the patients had requested MAID owing to hopeless suffering, loss of

dignity, loss of independence, pain, being a burden, and no prospect of recovery.¹³

In a 2015 report by the Oregon Public Health Division, people who requested MAID cited their primary end-of-life concerns as loss of autonomy (91.4%), decreased ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%).⁸ An Oregon study compared people who requested MAID to similar people who had advanced disease but did not pursue MAID using questionnaires and found that people who explored MAID had significantly higher levels of depression ($P=.03$) and hopelessness ($P<.001$) and lower spirituality ($P<.001$).¹⁴ However, the groups did not differ significantly on level of pain or perceived level of social support.¹⁴

The objective of this study was to explore the perspectives and experiences of people who pursued MAID in Canada in the first year after legalization. We investigated the reasons for choosing MAID and the hopes and fears of people who pursued MAID in Vancouver, BC, from February 6 to December 17, 2016.

— Methods —

This was a descriptive qualitative study that used thematic analysis of semistructured interviews with people who pursued MAID and their support persons. When little is known about a topic, descriptive methodologies are used to begin to understand characteristics of phenomena, upon which additional research and theorizing can be built.¹⁵ We designed this study informed by the writing of narrative theorists Bruner^{16,17} and Sarbin,¹⁸ and with an appreciation for Dewey's^{19,20} theory of experience, which draws attention to the value of personal experiences as sites for the development of knowledge.

After attending a consultation at a Vancouver clinic that provides MAID, patients who had shown an interest in talking about their experiences were provided with information about the study and invited to contact the research team if they wished to participate. We used purposive sampling. Only patients who were eligible for MAID were included in this study. No invitations were given if the physicians believed that it was inappropriate for language, logistic, or emotional reasons. In cases where patients had difficulty with communication, their support people were also invited to participate in an interview to further clarify the patients' perspective.

Participants contacted the research team and arranged a convenient time and location for the interview. They were given the option to stop the interview at any time if it became too emotionally difficult. A consent form was completed before commencing the interview. A list of interview questions was used to guide the semistructured interviews so that key topics were covered. At the convenience of the research participants, the interviews were conducted in person, by video, or over the telephone and lasted 30 to 60 minutes.

The interviews were audiorecorded, transcribed, and analyzed using thematic qualitative analysis.

For this study, it was important to us that the final research texts were descriptive without being overly interpretive and that the experiences of the participants were aggregated in a way that protected their confidentiality. The research team was composed of 1 physician (E.W.), 1 social worker (J.S.), 2 medical residents (A.N., S.H.), and 2 research assistants who had backgrounds in health sciences (M.K., A.J.). The medical residents were the primary interviewers and the whole research team participated in a thematic analysis of the transcripts, informed by the process of Braun and Clarke.²¹ The first reading of the transcripts was done individually by each researcher, during which time each identified emergent themes. As a group, commonalities were discussed and codes for further analysis were agreed upon. Secondary analysis was conducted by the research assistants where sections of the transcripts were highlighted per codes, and supporting verbatim quotations were pulled. A tertiary analysis of the documents that emerged was conducted by the whole research team.

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

— Findings —

Demographic information

Between February 6 and December 17, 2016 (inclusive), 113 people were assessed at the clinic for MAID and 68 were given information about the study and were invited to participate by contacting the researchers directly. Of the 68 people who were informed about the study, 23 were interested in participating and their experiences are captured here. Eleven patients were interviewed directly and 18 family members and friends were interviewed on behalf of another 12 patients. All the patients included in this study were eligible for MAID. Two of the participants received MAID between February 6 and June 6, 2016, a time when Canadians required a court order to have MAID, so they went through additional barriers such as hiring lawyers and preparing affidavits.

Patients ranged in age from 54 to 102 years and their diagnoses included organ failure, malignancy, and neurologic diseases (Table 1). Although they were all assessed by an urban physician, 16 of them lived in an urban setting, while 5 were semiurban and 2 were from rural communities. Sixteen of the patients had MAID, 6 were waiting for MAID at the time of the study, and 1 had a natural death. Of those who had MAID, 8 died at home and 8 died in a clinic or hospital setting. Of the support people who were interviewed, 5 were spouses, 9 were sons or daughters, 3 were friends, and 1 was a sibling.

Reasons for choosing MAID

With respect to the people's reasons for choosing MAID,

several themes emerged for which saturation was reached.

The most prominent theme was that people believed it was important to have autonomy and control over their own lives. They wanted to decide for themselves when their suffering was too great and they wanted to have end-of-life options that included MAID:

I feel that if you want to live until the very last moment and have tubes and machinery keep you alive ... then so be it. Go for it. I also believe that if I don't feel this way, you should respect my wishes as well I don't want to have to take matters into my own hands. I want options. I want choice. I deserve that. We all deserve that. (Patient H)

People also believed that their quality of life was unacceptable owing to the constant struggle with their health and function, a loss of the ability to participate in meaningful activity, or a loss of a sense of purpose such as work, hobbies, or other enjoyable activities:

In fact, when you live with something like this and life is such a struggle every day, you almost welcome the end. You go, "I don't want to struggle anymore." And it's not something that, you know, Zoloft or Prozac is going to be able to help. (Patient C)

It's not living; it's an existence and I want to end it. (Patient A)

Loss of independence and loss of function were also themes in the data. Many people had been strong willed and self-reliant before they became ill and struggled with being reliant on others, including family, for their basic needs and daily care:

He doesn't want to be incontinent. He doesn't want people cleaning him up or waiting in the hopes that somebody finds him to clean him up He's kind of a very dignified man, so he would find that a big struggle. (Spouse of patient F)

Loss of physical ability such as walking or use of hands was often cited as a reason to pursue MAID, particularly for people who had been very physically active in their lives:

The deterioration is ongoing ... inability to chew and swallow and speak. Physically, my right side is weaker than the left. I can't open a door with keys. A knife and scissors and zips are a real challenge. I can't do stairs or steps anymore and can no longer step into the bath. Lack of control of the bowels is a special misery. (Patient B)

Table 1. Characteristics of the 23 patients who requested MAID

PATIENT	AGE, Y	DIAGNOSIS	SEX	INTERVIEWEE	TIMING OF INTERVIEW
A	89	Paget disease	Female	Patient	Before MAID
B	76	ALS	Female	Patient, son	Before MAID
C	65	CANVAS (neurologic)	Female	Patient	Before MAID
D	70	Cancer	Male	Patient	Before MAID
E	80	Cardiomyopathy	Male	Patient	Before MAID
F	93	Cancer	Male	Patient, spouse, daughter	Before MAID
G	85	Lung disease	Female	Patient	Before MAID
H	54	Pulmonary fibrosis	Female	Patient	Before MAID
I	89	Heart disease	Female	Patient	Before MAID
J	95	Frailty	Female	Patient	Before MAID
K	68	Cancer	Male	Patient	Before MAID
L	94	Frailty	Male	Son	After natural death
M	66	ALS	Female	Friend	Before and after MAID
N	69	MS	Female	Spouse	After MAID
O	85	Pulmonary fibrosis	Female	Friend	Before MAID
P	62	Cancer	Male	Spouse	Before MAID
Q	72	Alzheimer disease	Male	Spouse	Before MAID
R	54	MS	Female	Sister	After MAID
S	71	Primary lateral sclerosis	Male	Spouse	Before MAID
T	87	CHF	Female	3 friends	After MAID
U	102	Frailty	Female	Daughter	After MAID
V	84	Organ dysfunction	Male	Daughter	After MAID
W	88	Cancer	Male	Son	After MAID

ALS—amyotrophic lateral sclerosis; CANVAS—cerebellar ataxia, neuropathy, and vestibular areflexia syndrome; CHF—congestive heart failure; MAID—medical assistance in dying; MS—multiple sclerosis.

Loss of ability to speak or communicate was another theme:

Not being able to speak. He was a wonderful storyteller and he wrote plays and he wrote songs and he can't communicate anything anymore. And I think that's the worst thing. Even when he was still at home, if we had people over, he would often stay in the other room. And I'd say ... "Why don't you want to come and be with us?" He said, "I can't tell stories anymore. Every time somebody makes a comment and I'd like to tell or say something about it, by the time I get it out, the whole group has moved onto another story. I can't participate anymore." It's really awful because he was the storyteller, the life of the party. (Spouse of patient S)

Suffering or fear of future suffering was another theme in people's reasons for pursuing MAID. In some cases, people had a diagnosis with a predictable course

and they wanted to end their life before they reached the final stages or had an unpleasant natural death, such as respiratory failure:

You will lose your speech. You will lose your ability to swallow, so you could choke to death. You could get a really bad flu and you're very susceptible to that so that could kill you ... susceptible to falls, so breaking a hip and not recovering All of it not very great. (Patient C)

Of note, pain was seldom mentioned as a reason why people chose to pursue MAID.

Hopes, fears, and wishes

All participants in our study felt very confident in their decision to pursue MAID. They stated that they did not have any fears about having MAID, although some feared that systemic barriers would prevent them from being able to have an assisted death and their suffering would continue.

People's preferences for the location for their death varied and included at home, in a hotel, in a clinic, or in a hospital. Some people preferred to be alone for their death or to have only a close loved one present, while others wanted many loved ones to be at their bedside and some form of ceremony such as dinner or exchanging of final words. As one patient described,

I want the actual act to happen at home, here. I don't do fuss well, so my son and his wife and a good friend will be there I asked my friend what will we do while waiting and she suggested playing cards. Why not! Perhaps I will have my favourite music playing. (Patient B)

People felt that having the opportunity to choose the date of their death was beneficial because they had time to meet with loved ones and to prepare.

Spiritual beliefs

The participants had various religious backgrounds. Of those who discussed their spiritual beliefs, 8 described themselves as atheist and 6 described themselves as very spiritual but without identifying with a specific religion. Two participants described themselves as religious and they did not feel that MAID conflicted with their religious beliefs.

Discussions with others

Patients felt supported when they told others of their decision to pursue MAID. For the most part, they only told a few close friends and family members because they did not want to have to debate or justify their decision. Some people felt very comfortable discussing their decision with many others.

— Discussion —

In this study, people's reasons for requesting MAID were loss of autonomy, loss of independence, loss of purpose and enjoyment, loss of physical and communication abilities, and suffering or fear of future suffering. There was considerable overlap between our findings for people's reasons to pursue MAID and the findings of previous studies from other jurisdictions. Our common findings with studies from the Netherlands¹¹⁻¹³ include functional impairment, dependency, loss of autonomy, fear of future suffering, and loss of all that makes life worth living. One difference is that the studies from the Netherlands reference pain and worrying about being a burden as factors contributing to unbearable suffering, whereas these factors were not cited by our participants. Our findings were more consistent with the findings of the Oregon Public Health Division, in that pain was not an important factor for patients who pursued MAID in Oregon.⁸ The reasons why people pursued MAID in

Oregon were in line with our findings: loss of autonomy, decreased ability to participate in activities that made life enjoyable, and loss of dignity.⁸

In other jurisdictions, malignancy is the most common diagnosis in MAID, at more than 70%.^{5,8,9} In this study, neurologic diseases and organ failure were slightly more common than malignancy. This might be because the study was initiated when MAID first became legal in Canada. As people with neurologic diseases and organ failure often live for many years with a poor quality of life while those with malignancy tend to decline more rapidly, we wondered if patients with neurologic disease who were waiting for the legalization of MAID might have accumulated relative to those with malignancy. Longitudinal tracking of the diagnoses of MAID patients in Canada will be important to further investigate this trend.

A strength of our method is that semistructured interviews are especially suitable for descriptive research because they allow the researcher to extend the conversation beyond standard questions and to follow the research participants' leads into new areas of conversation.²² As practitioners and researchers who ascribe to a biopsychosocial model of care,^{23,24} it was important to us that we look beyond clinical outcomes to understand how people experience health care. Also, by including support persons in the interviews we could capture the experiences of people who were no longer able to speak, which was a common situation for MAID patients and, therefore, an important perspective to include.


Limitations and areas for future study

As this study only included people who volunteered to participate, our results reflect the opinions of those who were eager to share their experiences. We are left wondering about the experiences of other people who sought MAID but who did not want to participate in this research. Another limitation of this study is that most participants were recruited from a single clinic in a single province, so the results are not representative of all of Canada. We focused on the experiences and opinions of people who pursued MAID; however, a richer data set of demographic information that included education and socioeconomic status would provide more context and understanding of the population studied. A study of public opinion in Alberta showed that those who had lower income, lower education, strong religious affiliation, and a conservative political affiliation had less support for MAID, highlighting the importance of the demographic context.²⁵

Future studies could investigate the opinions and experiences of family and friends of MAID patients, with interviews before and after the patient's death, to gain a better understanding of how this process affects loved ones. The level of pain experienced by people who choose or do not choose MAID could be investigated. It would also be important to determine what services

people had received for symptom management during the advanced stages of their disease.

Conclusion

During our study, the laws and regulations regarding MAID continued to develop, and there were few providers and clinics offering MAID. The experience was novel for patients, families, and physicians. Those involved had no one with whom to compare experiences. In the years to come, many physicians will be approached for the first time by a patient inquiring about MAID, and many Canadians will have a first experience with a family member or friend who pursues MAID. The results of this study are intended to facilitate a deeper understanding of the unique perspectives and experiences of people who pursue MAID and to provide some insight into their variable preferences for the social and physical environment for MAID. This can help inform decision making for physicians and governments regarding MAID provision .

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Contributors

Drs Wiebe, Shaw, Nuhn, and Holmes and **Ms Just** were involved in the initial design and planning of the study; **Drs Nuhn and Holmes** performed the interviews; **Ms Kelly** performed the transcription; and all authors were involved in the analysis and approved the final manuscript.

Competing interests

None declared

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