

Exploring the experience of supporting a loved one through a medically assisted death in Canada

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Abstract

Objective To explore the experience of family and close friends of patients seeking medical assistance in dying (MAID) in Canada.

Design Qualitative study using semistructured interviews.

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

Participants Eighteen support people for patients seeking MAID.

Methods Clinic patients seeking MAID identified their primary support people during consultations for an assisted death evaluation. Identified support people were invited to participate in the study, and those who were interested were asked to contact the interviewers. Semistructured interviews were conducted, transcribed, coded, and subjected to content analysis to elucidate common themes.

Main findings All participants were supportive of their loved one's wish for assisted death and they provided emotional and practical support in preparation for MAID. Support persons talked about the journey they went through from their loved one's diagnosis to the MAID request to the actual death. Some were initially opposed but changed their minds after seeing the suffering their loved ones endured. The time before the assisted death involved saying goodbye and, for some, ceremonial rituals (celebration of life, poems, singing, etc). Those interviewed after their loved one's assisted death found the death peaceful and reported that it offered advantages compared with natural death in their loved one's individual circumstances.

Conclusion This study provides insight into experiences of support people coping with a loved one who is seeking or has sought MAID in the context of a country unfamiliar with the legal process of a planned and hastened death. Participants were supportive of their loved one's wishes for assistance in death to end suffering and found the process to be peaceful overall.

Editor's key points

- ▶ This study provides insight into the personal journeys of relatives and friends who supported a loved one through the process of assisted death in Canada in the early days after legalization of medical assistance in dying (MAID).
- ▶ All friends and family in this study were supportive of their loved one's wish for assisted death after witnessing enduring suffering. Support people helped with preparations for MAID, but found it strange at times to be planning a death. Participants described the day their loved one had MAID as peaceful overall.
- ▶ Support people found MAID to have some advantages compared with natural deaths they had previously witnessed. Participants valued the opportunity to spend time with their loved one and to say goodbye.



Points de repère du rédacteur

► Cette étude nous permet de mieux comprendre le parcours personnel de parents et d'amis qui ont accompagné une personne chère à travers le processus de l'aide médicale à mourir (AMM) peu après sa légalisation.

► Tous les amis et les membres de la famille des patients les soutenaient dans leur décision de bénéficier de l'AMM après avoir été témoins des souffrances endurées. Ces personnes ont aussi contribué aux préparatifs de l'AMM, mais ont trouvé étrange par moments de planifier un décès. Les participants ont qualifié le jour où leur proche a reçu l'AMM de paisible dans l'ensemble.

► Les participants ont observé que l'AMM comportait certains avantages comparativement aux morts naturelles auxquelles ils avaient déjà assisté. Ils ont aussi apprécié cette occasion de passer du temps avec leur être cher et de lui dire adieu.

Étudier l'expérience du soutien à une personne chère ayant obtenu l'aide médicale à mourir au Canada

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Résumé

Objectif Étudier l'expérience qu'ont vécue les parents et les amis proches de patients qui avaient demandé l'aide médicale à mourir (AMM) au Canada.

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 Dix-huit personnes qui soutenaient des patients demandant l'AMM.

Méthodes Les patients de la clinique qui demandaient l'AMM ont identifié leurs proches aidants au cours des consultations visant à évaluer leur admissibilité à l'AMM. Les personnes identifiées ont été invitées à participer à l'étude, et on a demandé à celles qui étaient intéressées de contacter les interviewers. Des entrevues semi-structurées ont été menées, transcrites, codées et soumises à une analyse de contenu pour en tirer les thèmes communs.

Principales observations Tous les participants soutenaient leur proche dans sa décision de bénéficier de l'AMM, et ils ont offert un soutien émotionnel et pratique en préparation de l'AMM. Les proches aidants ont parlé du parcours qu'ils ont franchi depuis le diagnostic de l'être cher jusqu'à sa décision de demander l'AMM. Certains s'y étaient d'abord opposés, mais ils ont changé d'avis en étant témoin des souffrances endurées par leur proche. Le moment précédant l'AMM était l'occasion d'un dernier adieu et, pour certains, de gestes cérémoniels (p. ex. célébrer la vie, lire un poème, chanter, etc.). Les participants interviewés après la mort assistée de leur être cher ont mentionné que tout s'était déroulé de façon paisible et ont rapporté que l'AMM offrait des avantages en comparaison de la mort naturelle dans la situation particulière de leur être cher.

Conclusion Cette étude nous permet de mieux comprendre l'expérience que vivent les proches aidants auprès d'un être cher qui demande ou a demandé l'AMM, dans le contexte d'un pays peu habitué au processus juridique relatif à une mort planifiée et devancée. Les participants appuyaient la décision de leur être cher de bénéficier d'une aide à mourir pour mettre fin à ses souffrances; ils ont trouvé le processus paisible dans l'ensemble.

On June 17, 2016, Bill C-14 legalized medical assistance in dying (MAID) in Canada for competent adults with a grievous and irremediable condition that is intolerable, and where natural death is reasonably foreseeable.¹ This bill was enacted in response to the landmark *Carter v Canada* ruling on February 6, 2015, in which the Supreme Court of Canada struck down Criminal Code provisions preventing the right to an assisted death.²

Most Canadians are unfamiliar with the process of preparing for a planned death. Many might not have considered the possibility of MAID or having a loved one wish for a hastened death. Before the legalization of MAID in 2016, a Canadian who wanted to end his or her life to avoid further suffering would either have to commit suicide alone, risk criminal prosecution of those aiding in the death, or travel to another country to access euthanasia. Legalization of MAID allows family and friends to speak openly about MAID and assist their loved one in accessing it.

Assisted death is legal in Switzerland, the Netherlands, Belgium, Luxembourg, Oregon, Washington, Vermont, California, Hawaii, Colorado, and the District of Columbia and is legal by court ruling in Montana. A 2012 qualitative study in the Netherlands found that most relatives had a positive experience and valued the rituals that accompanied an assisted death (such as poetry, telling stories, and saying goodbye), but found that the idea of planning for a death was unusual, given that death is a topic that is not often discussed and in most cases the hope is that death is delayed.³ In a 2007 study in the Netherlands that interviewed relatives who were bereaved after an assisted death, more than 90% of the relatives believed that the assisted death had contributed positively to the overall end of life experience by ending the suffering of their loved one and allowing them to say goodbye.⁴

The objective of the present study was to examine the journey of family and close friends who supported a loved one through the process of MAID. In particular, we examined support persons' initial reactions to learning that their loved one wished to have MAID, how the support people's opinions of MAID evolved over time, their experiences with the death itself, and how they felt after the death occurred.

— Methods —

A qualitative approach was chosen to elucidate the detailed and rich perspectives of the participants. We employed individual semistructured interviews to allow family and close friends ("support people") to discuss their experiences freely.

The study was conducted at a clinic in Vancouver, BC, that provides MAID services. During MAID consultations, patients identified the family and friends who were their primary support. These support people were

then invited to contact the interviewers if they were interested in participating in the study. Interviews were conducted by telephone, e-mail, or video conferencing, according to participant preference. Two resident physicians who did not work at the clinic conducted interviews (S.H., A.N.).

Participants were asked about their initial reactions to learning their loved one was interested in MAID, how their perspective evolved over time, and the experience of planning for the death. Those interviewed after their loved ones had died were asked about the assisted death itself.

The interviews were audiorecorded (when conducted over telephone or videoconference) and transcribed. We then applied thematic content analysis to the data. Five researchers, including the 2 resident physicians who performed the interviews (S.H., A.N.), a family physician at the MAID clinic (E.W.), a research assistant (M.K.), and a social worker (J.S.), read each transcript. Five readers with different perspectives helped to increase the trustworthiness of the data through triangulation. These codes were then compiled into categories and themes. Participant recruitment was conducted from February to October 2016.

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

— Findings —

Eighteen support people were interviewed between February and October 2016. Interviewees included 9 adult children, 5 spouses, 3 friends, and 1 sibling of 15 individual clinic patients who had requested MAID. During this time period, 94 patients were assessed for MAID and 36 had completed MAID deaths. There were 67 support people identified and 50 were invited to participate. All the MAID deaths were by physician-administered intravenous medications. **Table 1** provides details about interviewees and the patients they supported. The main themes that emerged from the interviews are described below.

Reactions to learning about their loved one's interest in MAID—all were eventually supportive. Most support people were not surprised when their loved ones first expressed an interest in pursuing MAID. In some cases, they had discussed death and euthanasia for many years, even before becoming unwell:

I knew from the history of just growing up with my dad that he was pretty clear on not ever wanting to be a burden to anyone and also not wanting to suffer in dying ... he'd made some reference before he was sick, that he was thinking that he would like to try to find some way to be able to be in control of his own death. (Participant G)

Table 1. Demographic data for the interviewees

SUPPORT PERSON INTERVIEW CODE	RELATIONSHIP TO PATIENT	PATIENT'S DIAGNOSIS	TIMING OF INTERVIEW
A	Child	Organ failure	After natural death
B	Friend	Neurologic	Before and after MAID
C	Child	Neurologic	Before MAID
D	Spouse	Neurologic	After MAID
E	Friend	Organ failure	Before MAID
F*	Spouse	Cancer	Before MAID
G*	Child	Cancer	Before MAID
H	Spouse	Cancer	Before MAID
I	Spouse	Dementia	Before MAID
J	Sibling	Neurologic	After MAID
K	Spouse	Neurologic	Before MAID
L†	Friend	Organ failure	After MAID
M†	Child	Organ failure	After MAID
N†	Child	Organ failure	After MAID
O	Child	Organ failure	After MAID
P	Child	Organ failure	After MAID
Q	Child	Cancer	After MAID
R	Child	Organ failure	After MAID

MAID—medical assistance in dying.

*F and G were support people for 1 patient.

†L, M, and N were all support people for 1 patient.

Most support people thought that the patient's interest in having an assisted death fit with their loved one's long-standing values: "I thought it was in line with her personality and her current situation in terms of her health. I thought it was the most normal thing for her to request it." (Participant R)

One wife commented that her husband "used to be an airline pilot, so he's used to being in control." (Participant H)

A few of the participants expressed tension between supporting their loved ones and being upset about their decision to have MAID:

I was first saddened and somewhat shocked at her decision. Likewise, I felt it somewhat drastic ... knowing that it was not only a conscious decision on her part, but also one that she would not have made lightly had other alternatives been available. In retrospect, I now think it was a very brave and courageous decision on her part. (Participant N)

In some cases, support people tried to avoid oppositional views by not discussing MAID with certain people.

I knew that not many people would be ready to talk about it, so I am being careful on who gets to know what really happened and the official version on the people who don't need to know ... I don't want to have any moral debates on it with anyone. (Participant R)

Interviewees felt that their sadness regarding the upcoming death of their loved one was overshadowed by hoping for the end of their loved ones' suffering:

The hardest thing for me was to see [her] so happy that she could choose to die, while for me it would be so sad to lose her. I had to hold both of these feelings at the same time and be OK with them. I am now able to do that. (Participant E)

A number of the patients had considered the option of suicide to end their suffering. Interviewees discussed assisted death as a more peaceful alternative to end suffering:

He was quite adamant that he was just going to do himself in ... I've been able to kind of get his agreement that he won't do that, and that we will pursue this so that he can have a peaceful death and it won't be as traumatic for me. (Participant I)

One spouse feared repercussions of family becoming implicated in aiding suicide if assisted death were not available to his wife:

My wife at one point could have killed herself with the pills that she had ordered ... it became impossible for her, and because she couldn't move her hands

properly ... it would have put other people around her in jeopardy, legal jeopardy. (Participant D)

Support people helped in preparation for MAID—they found it strange at times to plan for a death. Interviewees helped their loved ones by providing emotional and practical support in preparation for MAID: “It’s kind of an overwhelming process ... you kind of take it day by day.” (Participant C)

One friend discussed the support she provided: “On the one hand [I am] relishing her friendship and enjoying the contact with her, and on the other hand, problem solving with her around what to do and how to help her achieve her goal.” (Participant B)

Some discussed strange feelings regarding planning for a death: “I just kind of want to know ... but I am not asking him to come up with a date, an arbitrary date. I think that’s unfair ... I think that he’ll choose it when he’s ready.” (Participant K)

Another said, “[She] chose her exact date of death based on who was in town, what things she needed to get done, and whether she could attend a final book club ... we had great laughs over this.” (Participant E)

Some expressed fears over possible difficulties in accessing MAID:

I guess what I feared is that ... we wouldn’t be able to have it happen ... because of litigation or because of interference from someone or because we couldn’t find the right person [and] that it wouldn’t be painless and easy. (Participant G)

Another support person said,

All of a sudden, we learned that there were spaces available at [hospice with religious affiliation] but that became potentially problematic as they had no policy in place and nor did other palliative care facilities for people who had made the decisions for physician-assisted death ... that became an additional barrier, which becomes problematic when you look at publicly funded hospice care that’s run by religious organizations. (Participant A)

Support people also discussed reconnecting with family and friends as well as celebrating the person’s life in the time leading up to MAID:

I arrived in Vancouver 5 days prior to the day of her death. We had told everyone who was close My brother who hasn’t had a good conversation with her in 10 years ... they had 4 or 5 good conversations ... it was almost like a perfect week for her, when everyone would call her and share stories for her ... her grandchildren would call her every single day, and how many grandparents get that? (Participant R)

A daughter said,

We shared with him the things we loved and were grateful for and the funny things. It was so beautiful ... we said our love and our goodbyes I am always one for ceremonies; I think it is so important. (Participant P)

The day of assisted death and reflections afterward: a planned death day was an interesting and unusual experience and was thought to be peaceful overall.

Regarding being present on the day of their loved one’s death, participants considered involving rituals and ceremonies:

I like rituals ... you know the usual ones, music, flowers, etc ... it wasn’t necessary I didn’t get a sense that she wanted anything else, other than to proceed to what was her goal ... you don’t need the stage management when your major goal is to have a peaceful death ... if you can just be there with them so you’re as close to them as possible, I think that’s what’s critical. (Participant B)

A support person described the unusual experience of spending time with a person when both know it is that person’s last day alive:

We had some funny moments that day because I had the window open and she said, “Can you close the window? I don’t want to catch a cold.” Everything we said was absurd ... she said “Well, I better take my vitamins because I have a big day today.” (Participant R)

One support person found the day stressful because her loved one was transferred on the day of death from a religion-affiliated institution to another that would permit MAID:

What was horrible—horrible—was to hear him scream and cry out every single bump ... it could have been so beautiful and peaceful if she [the physician] could have just come into the room there. It could have been that simple and that beautiful for him, and for us too. (Participant P)

Support people who had witnessed the assisted death found it “sad [and] though it was and will remain so for some while yet, it was peaceful, and graceful.” (Participant N)

One spouse said,

Having lived through one, I can’t believe how wonderful, if I can put it in those terms, passing away can be. My wife was very comfortable, very serene,

surrounded by friends, family. The time was her choosing, and that was something that was extremely important and very, very meaningful. (Participant D)

Comparing MAID to naturally occurring death: MAID was thought to provide some advantages. The participants who were interviewed after the death found MAID to be more peaceful; they valued the ability to spend time with their loved one and to say goodbye. “I believe the process may have been easier. I did fear for a difficult or prolonged death for my mom. With assisted suicide I knew she did not suffer and she died very peacefully.” (Participant O)

Some participants discussed the value of being able to say goodbye:

For us to spend all of that time before was such a privilege She loved all of those talks on the phone. She probably spent 6 hours a day on the phone for those 7 days before her death so emotionally I think there is a real sense of closure. I think everyone dreams of dying in their sleep because it is painless but it is painful for others. (Participant R)

— Discussion —

This study provides valuable insight into the personal journeys of relatives and friends who supported a loved one through the process of assisted death in Canada, a country new to the possibility of legalized assisted death.


Participants in this study all reflected positively on the assisted death overall. Support people who were interviewed after the death compared their loved one’s assisted death to other natural deaths they had seen in the past and believed the assisted death had advantages similar to those described in a previous study conducted in the Netherlands.³ A 2009 study in Oregon compared the mental health and reactions of bereaved relatives of patients who died from assisted death versus natural death (from cancer or amyotrophic lateral sclerosis).⁵ They found that the family members whose loved one had an assisted death experienced improved mental health outcomes and less regret about the death when compared with natural deaths. Family members of those requesting an assisted death felt more prepared and accepting of the death. A similar study from the Netherlands in 2003 compared grief responses of family and friends of those with cancer who died of euthanasia versus natural causes.⁶ They found those bereaved as a result of euthanasia experienced less grief and posttraumatic stress. They postulated that these findings might be related to having the opportunity to say goodbye while the loved one was cognizant, being prepared for the death, and talking openly about the death after euthanasia was requested.⁶

Limitations and areas for future research

The relatives and friends who participated in our study might have been more likely to be supportive of MAID compared with those who were not identified as primary support people or those who did not contact us to participate in an interview. We might have missed the perspectives of those who were more ambivalent, opposed, or private in their opinions about MAID. Another limitation is that we conducted interviews at a single clinic that focused on MAID provision and so we were not able to capture the variety of experiences of support people whose loved ones were accessing MAID in other locations and settings (such as inpatients, from their own family physicians, outside of Vancouver or British Columbia). Although our study captured the participants’ description of how their attitudes about MAID had changed throughout the process, we were not able to follow these changes over time with only 1 interview.

Areas for further inquiry could include expanding interviews to other parts of Canada. Purposive sampling could be done to capture the views of support people who might be more ambivalent about or opposed to MAID to learn more about their concerns and views. Research into the emotional and mental health outcomes of support people involved in helping loved ones with MAID in Canada could also be conducted.

Conclusion

Participants in our study described their experiences supporting a loved one through the MAID process—from learning about the wish for MAID through to the death—in a country in which an assisted death has only recently been legalized. All were supportive of their loved one’s wish for assisted death after seeing the suffering endured, and they provided emotional and practical support in preparation for MAID. Interviewees found the assisted death peaceful and thought it offered certain advantages compared with a natural death in their loved one’s specific circumstances. This study provides insight into the new experience of Canadians supporting a loved one pursuing an assisted death. 

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Contributors

Drs Holmes and **Nuhn** conducted the interviews. **Drs Holmes, Wiebe, Shaw,** and **Nuhn,** and **Ms Kelly** coded the data. All authors contributed to interpretation of the data and preparing the manuscript for submission.

Competing interests

None declared

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