Experiences of patients and their support people with medical assistance in dying in Canada (MAiD)

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Disclosures

None

Objectives

To explore the experiences and perspectives of Canadians:

1. requested and were eligible for MAiD
2. those people supporting them

Methods

Design: Semi-structured interviews by two residents (physicians in training).

Setting: An urban clinic in Vancouver, BC, that provides MAiD services.

Participants: Clinic patients seeking MAiD Feb-Oct 2016 and those who were identified as their primary support people during consults for an assisted death evaluation

Analysis

- Each researcher read each transcript and identified emergent themes.
- The group discussed the themes and agreed upon codes
- The research assistant coded transcripts and identified supporting quotations
- The group met for further analysis of the themes

Findings

Patients n=23

- Age: 54 to 102 years
- Diagnoses: organ failure (10), neuro (7), cancer (6)
- Interviews: 11 patients directly and 12 through their support people
- 16 urban, 5 sub-urban and 2 rural
- 13 women, 10 men

Support people n=18

- 9 adult children
- 5 spouses
- 3 friends
- 1 sibling
- 10 interviewed after, one before and after, 7 before

Themes

Autonomy and control

“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.” (woman with pulmonary fibrosis).

Loss of ability

“ 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.” (woman with ALS)

Loss of communication

“He was always a very engaging man and loved discussion and conversation and he was just not able to participate in that. He couldn’t write, he couldn’t speak… He kind of sat there being aware of what was going on around him but couldn’t actively participate.” (Daughter of man with Parkinson’s).

Loss of dignity

“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 man with cancer)

Hopes, fears, and wishes

Most expressed confidence and talked about the details of their planned deaths

“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 favorite music playing.”

Telling others

Most felt supported by those they told

A few told lots of people, but most told only the close friends and family

“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” (sister of woman with MS)

Spirituality

They had a variety of religious backgrounds

- 8 atheists
- 6 “spiritual”
- 2 “religious” but they did not feel that MAiD conflicted with their religious beliefs.

Pain

Pain and other physical symptoms were seldom mentioned and then briefly

Support people

- Wanted to talk about their loved one (not themselves)
- All supportive, although not all immediately
- They all talked about the journey they went through, from diagnosis to death

First reactions

Most support people were not surprised when their loved one first expressed an interest in pursuing MAiD.

"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" (daughter of man with cancer).

Changing attitude

A few of the participants were taken aback when their loved one brought up interest in 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” (son of woman with organ failure).

Saying goodbye

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 six hours a day on the phone for those seven 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" (daughter of woman with organ failure).

The day

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

“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“ (friend of woman with neurological disease).

One negative experience

One support person found the day stressful because her loved one was transferred on the day of death from a religious-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” (daughter of man with cancer).

Humor

A support person described the unusual experience of spending time with a person when both know it is their 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" (daughter of woman with organ failure).

After

Most were very positive

“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” (spouse of woman with neurological disease).

Discussion

Reasons

Similar to findings in the Netherlands: functional impairment, dependency, loss of autonomy, fear of future suffering, and loss of all that makes life worth living.

Dees M, Vernooij-Dassen M, Dekkers W, Vissers K, van Weel C. Unbearable suffering': A qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics*. 2011;37:727-734.

Support people's reactions

Positive reactions from support people similar to findings from the Netherlands - less grief and post-traumatic stress reactions

Swarte NB, Van Der Lee ML, van der Bom JG, Van Den Bout J, Heintz AP. Effects of euthanasia on the bereaved family and friends: a cross sectional study. BMJ. 2003 Jul 24;327(7408):189.

Limitations

- Only one centre
- Only first 9 months
- Mostly single interviews