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Title: Canadian family members’ experiences with guilt, judgment and secrecy during medical assistance in dying (MAID): a qualitative descriptive study
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Reviewer 1: Dr. Rosanne Beuthin
Institution: University of Victoria Faculty of Human & Social Development
General comments (author response in bold)

1. Under theme of guilt (pg 5 line 39-40): indicates 2 participants spoke of being traumatized to see someone dead. Was this their first experience in seeing a person dead (I note this was asked in the interview guide under background), and if so, I wonder if this is not to be expected, as in our society this has become a more rare experience? The trauma or shock may be just that, and not specific to an assisted death.
We have clarified: “As it is rare nowadays for people to witness death and see a body, their trauma and feeling haunted may not have resulted from MAID itself.” (p. 7)

2. I am curious about the theme of secrecy, and if the research team considered “privacy” or “confidentiality.” Our society tends to think of keeping a secret as aversive, and yet secrets are highly individual and can be negative, but also can act as a very powerful, helpful and appropriate response, especially for those living with life threatening illness. (Holding Secrets While Living With Life-Threatening Illness: Normalizing Patients’ Decisions to Reveal or Conceal. QHR, 2019. Bruce, A., Beuthin, R., Sheilds, L. et al. doi.org/10.1177/1049732319887714).
Thank you for bringing this to our attention. We have read and discussed your article. Secrecy was a term initially used by participants, then we asked about it. Privacy and confidentiality did not fit with the data or interpretation.

3. I wondered about lines 48-49 under interpretation and if I may offer this suggestion:
Interpretation
Responses to the death and loss of a loved one vary and hold a multitude of complex experiences. This research captures important information to increase understanding about one aspect common family members may experiences during MAID: guilt, judgment and secrecy.
These lines have been revised to: “This research captures important information to increase understanding about some unexpected yet common family member experiences during MAID: guilt, judgment and secrecy. MAID is a complex experience and individuals respond to death and loss differently” (p. 8)

4. I found your sentence in the body of the paper (page 8, line 12-15), under Interpretation, to be more reflective of the data and quite impactful: “a significant minority of participants unexpectedly found themselves managing guilt, judgment and/or secrecy, which may further complicate grieving and bereavement….”
I wondered if this sentence might be a better choice in the abstract, under Results, to replace this sentence: “Multiple participants experienced guilt and/or distress from watching their family member die and being involved in planning their death.”
The abstract sentence has been replaced as you suggest. (p. 2)

5. Wondering about verb tense:
Medical assistance in dying (MAID) was decriminalized in 2015 in Quebec1, 2016 in Canada, and eligibility criteria was were amended in 2021.
The verb tense has been changed as you suggest. (p. 2)

6. Under Interpretation,
a) I am wondering if this is the correct reference you intended to use: “A survey could increase understanding about the knowledge gap between family members’ (and others involved in MAID) having complicated grief/bereavement (29).
Due to the editors’ and reviewers’ suggestions about more appropriate approaches than a survey and being mindful of space as we needed to add information to this paragraph, we have revised the limitations to reflect the qualitative approach. (p. 9)

b) I am hesitant to suggest use of the term “race” as an indicator (“To ensure representativeness of family member experiences, future researchers should collect demographic data (e.g., race, education, income, religion, rural/urban, etc.),” given current emergent understanding that race is a social construct and not a biological phenomenon. The term "race" is now considered by many to be damaging, in that racism goes hand in hand with colonization. Within our one human race, there are groups of people who practice different cultures. This may be an opportunity to help shift data collection in this direction. Maybe the term “race” could be replaced with “culture” in your manuscript?
(Reference: Delgado, Richard, and Jean Stefancic. Critical Race Theory (Third Edition): An Introduction, New York University Press, 2017.
Thank you for the helpful information. We initially used “race” as this is the term Health Canada and some CMAJ Open authors have used when discussing socio-demographic data collection. We have changed “race” to “ethnicity” to be in line with previous articles published in CMAJ Open and hope you will find this acceptable. (p. 9)

Reviewer 2: Dr. Anita Acai
Institution: McMaster University
General comments (author response in bold)

ABSTRACT: I would suggest including the type of qualitative design (i.e., qualitative description) in the methods section. Otherwise, the abstract is appropriate.
This has been added (p. 2)

INTRODUCTION: The introduction is surprisingly short, although numerous articles are referenced. It would be helpful to provide some further context and history about MAID in Canada. I would also encourage the authors to present a clearer justification for their work, as the fact that not much is known about family members' perspectives on MAID is not a convincing rationale for undertaking this research. Instead, the authors could focus on the importance of their work in helping healthcare providers provide compassionate care to not only those who are undergoing MAID but also to their family members who remain living once the process is complete.
Additional context and history about MAID in Canada and information about compassionate care have been added to the introduction and it has been expanded. (p. 3)

METHODS: I would suggest that the authors define qualitative description methodology and explain why it was the most appropriate design for their work. The quotes shared throughout the manuscript suggest that the data collected were quite rich, so I wondered why the authors did not use a more interpretive methodology to bring out some of this richness and more nuanced perspectives that are not currently captured in the findings (e.g., deep and complex emotionality, the death of a loved one resulting in the "death" of relationships with friends and other family members, etc.).
We have added information about the methodology and explained its appropriateness in the manuscript. A qualitative descriptive methodology does not go as deep with interpretation: it is "less interpretive than "interpretive description" in that they do not require researchers to move as far from or into their data … The description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language" (Sandelowski, 2000, p. 335-6 – full citation in manuscript). This methodology choice guides us to adhere closely to participants' original words. (p. 5)
We also added information to the Interpretation section: "This research captures important information to increase understanding about three unexpected yet common family member MAID experiences: guilt, judgment and secrecy. Dying and MAID are complex experiences and individuals respond to death and loss differently. Many family members did not feel adequately prepared for MAID or the aftereffects. This, along with being involved in planning death and watching someone die, led to some participants experiencing guilt and trauma. Some did not expect to be judged by relatives, friends, religious people and/or healthcare professionals who opposed MAID. Many interviewees kept MAID secret in some form; some never told anyone about MAID while others selectively told trusted supporters. Most family members said they were unprepared for unexpected surprises, perhaps because they lacked experience with death and MAID." (p. 8)

Based on the third sentence in the methods ("Although interviews contained diverse information about family members' experiences... [p.3]) and the questions in the interview guide, I wondered if this study was a subanalysis of a larger dataset. If so, that should be clearly outlined in the manuscript.
We clarified this is a sub-analysis in the methods: "®. "While analyzing transcripts as interviews occurred, we noted that many participants discussed different types of unexpected experiences and we performed a sub-analysis of this." (p. 4)

The sampling strategy is described as convenience sampling, but this does not seem to match the authors' description of their approach. The authors' sampling strategy appears to have been purposive, with a clear strategy to recruit a wide range of participants from across Canada.
This change has been made: "Recruitment used convenience and purposive sampling..." (p. 4)

Another sentence related to the sampling strategy ("Anyone who experienced a MAID death in Canada was included" [p.4]) is confusing. The authors' sampling strategy could not possibly have captured the family members of everyone who experienced a MAID death in Canada; therefore, this statement should be amended. I would also suggest adding a sentence to describe the steps in the recruitment process that came after advertising the study—e.g., if someone was interested in participating, did they email the study team and then complete screening to determine if they were eligible to participate?

We clarified these in the manuscript: "Any family member who experienced a MAID death in Canada was invited to email us, screened for eligibility, signed the consent form, then booked for an interview." (p. 4)

Additionally, several aspects of the authors' analytic strategy require clarification. For example, it was stated that, "We grouped similar codes about unexpected surprises together and 3 prevalent themes emerged" (p.4). I was surprised that coding 45 transcripts containing rich data (based on the quotes) resulted in only three simple themes: guilt, judgment, and secrecy.
We clarified the analysis, themes and categories throughout the manuscript and added Table 1. We have clarified in the manuscript that this is a sub-analysis of a larger study (see above comments). (pp. 4, 5, Table 1)
I suspect that some more nuanced themes could be developed from such a dataset, with more "depth" added to the themes (themes are usually more than one word; otherwise, they are more resemblant of categories). Based on the limited nature of the themes, it is difficult to understand how the authors "looked for codes that contradicted, supported, or helped clarify it [each theme]" (p.4).
The themes are listed in Table 5 and we added each theme to the manuscript: "we grouped similar codes within each category together to create themes" (p. 5)
Also, the categories referenced in the statement, "…we grouped similar sentences within each of the 3 themes together to create categories" (p.4) do not seem to be presented anywhere.
These are in Table 5 and in the results. (Table 5, pp. 5-9)
Lastly, I would suggest that the authors avoid terms such as "emerged" when describing the development of their themes, as this term is suggestive of a positivist or post-positivist epistemological orientation to research that is inconsistent with qualitative research. In qualitative research, themes are developed by the researchers and may look different depending on their backgrounds, experiences, and values.
We have changed this to: "For the next 25 interviews, we coded all sentences discussing unexpected surprises and developed 3 categories: guilt, judgment and secrecy. To round out each category, we looked for codes that were new or contradicted, supported, or helped clarify each category" (p. 5)

The authors noted that, "Data collection ended when data saturation was achieved" (p.4). I found this statement to be inconsistent with the fact that the authors collected data from 45 participants but only developed three themes—would data saturation not have occurred well before 45 interviews?
We have clarified this is a sub-analysis and added: "As MAID occurred between 2016-2021 and participants were heterogeneous, data saturation occurred when no new themes were identified in sub-analysis" (p. 5)

The authors also indicated that, "Our respective disciplines as healthcare researchers, provider and student and identities as cis-gendered White women shaped data interpretation" (p.4). How? Did any of the authors have any personal or professional experiences with MAID and/or death and dying that could have influenced the study?
We have clarified: "Our disciplines as healthcare researchers, provider and students and identities as cis-gendered, educated White women shaped data interpretation as we are neither involved in nor experienced with MAID. Data were collected and analyzed from a position of middle-class heteronormativity and White privilege, thus we may have overlooked experiences important to participants who do not have such privileges." (p. 6)

Were there any unique ethical considerations in conducting this study, given the sensitive nature of the topic? For example, were the interviewers trained on what to do if a participant became distressed during the interview?
We have clarified: "Although we could refer to Bridge C-14, DWDC or NSH MAID program for support, no participants were." (p. 5)

RESULTS: As I noted earlier, I feel that the authors may have limited themselves in their interpretation of this data set, as they could have presented a much deeper and compelling analysis—consistent with the power and purpose of qualitative research. There is deep emotionality reflected in participants' words (e.g., "…I almost felt like I was an accomplice to murder" [Box 1]), and for many, witnessing a family member experiencing MAID appeared to be a deeply complex and challenging experience that went beyond simply guilt, judgment, and secrecy. For example, one participant stated, "I didn't want her to die, but I didn't want [her] to be afraid," (Box 1), perhaps reflecting that they felt a need to suppress their emotions during the MAID experience to stay strong for their family member. What might be the longer-term implications of this kind of emotional suppression? I wonder, too, if some participants were working through a complex set of contradictory emotions, such as guilt and shame coupled with a sense of relief, and how they navigated this process.
A deeper analysis is presented in Table 5. The qualitative descriptive methodology approach does not fit with a deep interpretivist approach. Qualitative descriptive methodology is "less interpretive than "interpretive description" in that they do not require researchers to move as far from or into their data. ... they do not require a conceptual or otherwise highly abstract rendering of data … The description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language" (Sandelowski, 2000, p. 335-6 – full reference is in manuscript). This methodology choice guides us to adhere closely to participants' original words. Each Box has a deeper analysis. (Table 5)

While I acknowledge that the authors may have been contending with some space limitations, I found that the presentation of the results was weakened by the references to the quotes in the "boxes," as I kept having to scroll back and forth between the text and the boxes with the quotes. It would be very helpful if the authors could embed a few of the most salient quotes attached to each theme directly in the text.
We have rewritten the results and refer to Table 5 so the text flows better. *CMAJ Open* style indicates not to put quotes in the main text, rather in a table. (pp. 5-9)

Regarding the participant demographics presented in Table 1, it would have been helpful to know more about the gender of participants in the sample.
Unfortunately, we did not ask this question to participants. We have clarified: "To ensure representativeness of family member experiences, future researchers should collect demographic data (e.g., gender, ethnicity, education, income, religion, rural/urban, etc.)" (Table 3)

INTERPRETATION: Although this section appropriately recounted the main findings of the manuscript and connected it to helpful literature, the practical recommendations at the end can be refined (e.g., recommending that a survey be conducted seems too simplistic). Instead, the authors could explore the role that different types of educational and support initiatives for family members (e.g., arts-based approaches, counselling,

support groups, etc.) could play in helping family members manage their experiences. There is lots of work from other domains (e.g., palliative care) that could be applied here.
We have clarified: "Future researchers could examine whether family members benefit from receiving information about managing guilt, judgment and secrecy. Researchers could study whether there is a relationship between experiencing guilt, trauma and complicated grief. They could also test different types of educational and support initiatives that could help family members manage their experiences (e.g., arts-based, counselling, support groups, etc.)."
Thank you for your helpful suggestions, we hope it is ok if we have used some of your wording in the article. (p. 9)

LIMITATIONS: Were any steps taken to help reduce any sense of coercion that Nova Scotia participants may have felt, given that they were contacted by the nurse navigator and "… may have felt obliged" (p.7) to participate?
We have clarified: "As the nurse navigator phoned NS participants and invited them to participate, she may not have contacted families without telephones and some may have felt obliged. To avert coercion, interviewers consented each participant and indicated they could withdraw from the study."
How might collecting race data, as suggested by the authors, influenced the findings? Might ethnicity have been more relevant, given potential differences in cultural views on death and dying?
We have clarified: "Ethnicity was not collected for the first 20 interviewees; 24 of the next 25 participants were White. Interviewing diverse participants could identify cultural and social differences about death and dying, which could enrich the data." (p. 9)
What do the authors mean by "variety of family members" (p.7)? Most appear to have been the children of a family member receiving MAID and other family member types were less prevalent.
This has been revised to: "Family members are not from all provinces and territories and thus may not be representative of all experiences." (p. 9)
Given that this is a qualitative study, why was the use of different probing questions considered a limitation?
This statement has been removed.

INTERVIEW GUIDE: There is a note on the first page of the interview guide (Q1: "Check with Jocelyne about this") that the authors may wish to remove for publication purposes.
This has been removed. (Supplemental file)