

Article details: 2020-0163	
Title	How the experience of medical assistance in dying (MAiD) changed during the COVID 19 pandemic in Canada: a qualitative study of providers' experience
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Reviewer 1	Nicole Chau
Institution	Medical Oncology, BC Cancer, British Columbia
General comments and author response	<p>The authors should be commended on this manuscript which provides new insight on the MAiD experience during COVID 19 in Canada as there is very little literature in this area. The qualitative methods used were generally acceptable for descriptive qualitative research and several themes are reported by MAiD providers and coordinators.</p> <p>1. The authors acknowledge the significant study limitations including a very small sample size which is unlikely to reflect the general population of MAiD providers (which is also unknown), and the short duration of data collection within the context of the COVID 19 pandemic trajectory.</p> <p>1a. Other limitations that were not acknowledged pertain to the interview guide which could have been strengthened with testing before administration in the study to refine questions. Semi-structured interview guides do not need to be tested in the same way as surveys or questionnaires.</p> <p>1b Additional data which could have been collected or reported include how many assessments were cancelled or rescheduled, how many were delayed due to establishing virtual witnessing, how many providers were re-deployed to 'COVID work' and therefore unavailable for MAiD, how many assessments were delayed due to shortage of propofol, and what methods of virtual witnessing were used. This was not a quantitative study. A qualitative study with semi-structure interviews is not suited to that kind of data collection. We agree that this may be helpful to investigate in the future, but this is beyond the scope of our study.</p> <p>2. Due to these limitations it is difficult to more meaningfully discern the impact of COVID19 on the MAiD experience or better support the conclusion that more telemedicine and virtual witnessing, or other changes, will improve care. We believe that the findings of this study are meaningful regarding the impacts of COVID on the provision of MAiD as experienced by key informants who had experience providing and coordinating MAiD.</p> <p>We have clarified the ways in which more telemedicine and virtual witnessing will improve care and have provided an additional reference about this:</p> <p>Providers and their institutions also developed new systems and protocols to adapt to the challenges posed by the pandemic. Some of these adaptations were very helpful and will remain in place after COVID is over. For example, although telemedicine assessments are not ideal for every patient, more virtual witnessing and assessing could decrease delays and decrease travelling for both patients and providers (16). This is particularly valuable for individuals at the end of life, for whom getting to appointments outside of their home or community may be burdensome (18). Lines 232-246</p>
Reviewer 2	Lara Khoury
Institution	Medicine, The Ottawa Hospital, Ottawa, Ont.
General comments	This is an incredibly important topic and I commend the authors on tackling it.

and author response

I have a few comments/concerns to share with the authors:

1. I have difficulty accepting that this was truly the experience of MAID patients during the pandemic, when only MAID providers were interviewed. It would have been more convincing and more powerful if the interview questions were directed at the patients and their loved ones. Understandably, this is not easy to do; nevertheless, one cannot deduce how patients truly felt, simply from asking MAID providers about the experience of the patients. Furthermore, based on the answers provided by MAID providers, one did not get the impression that patients and caregivers shared how they felt necessarily with their providers. Rather it was the observation of providers and the deduction they made about how the patients must have felt that the authors shared with us. Therefore in my opinion, this study was about the experience of the providers and how they felt the pandemic impacted their patients and their access to MAID services. By interviewing providers who had experience before and during COVID with multiple patients, we could get a broader perspective and many examples. Each patient or family member would only have one story. This study is about what the providers observed and we have made this clearer throughout. Our title and introduction are clear that this paper is about providing MAiD not about having MAiD. It is noteworthy that the participants spent most of their time and emotion discussing patients and not themselves.

2. Authors mention that patients felt they had decreased rapport with providers given the use of virtual assessments. However, the examples provided were all about providers feeling removed, and feeling strange that they have to wear the PPE and can't hug or hold patients/loved ones' hands. Again, this is not the experience of the patients, rather of the providers themselves. We have made it clearer that the providers felt that they had more difficulty establishing rapport with patients:

The second most important theme was about the increased challenges for providers in establishing rapport due to using telemedicine assessments and personal protective equipment (PPE). Many said they felt a decreased closeness because they were unable to touch or hug at the time of provision (Box 2).

Lines 205-208

3. Authors made the suggestion that moving forward, given the poor experience patients experienced by not having in person assessments, institutions have decided that they should continue with virtual assessments which will result in "better care":

"There were many logistical challenges to MAiD providers during COVID, including sourcing PPE, using more telemedicine in situations where they would have preferred in person visits and trying to keep safe in situations where family members wanted to be close. Some adaptations these providers and their institutions made will remain after COVID is over and will help provide better service in the future."

If virtual assessments do not provide a good patient experience, then one cannot deduce that the accommodations made will result in "better patient experience". We have made it clearer that virtual assessments are not appropriate for everyone but have other benefits such as reducing delayed assessments, reducing travelling for both patients and providers. We have also provided a reference for this:

Providers and their institutions also developed new systems and protocols to adapt

to the challenges posed by the pandemic. Some of these adaptations were very helpful and will remain in place after COVID is over. For example, although telemedicine assessments are not ideal for every patient, more virtual witnessing and assessing could decrease delays and decrease travelling for both patients and providers (16). This is particularly valuable for individuals at the end of life, for whom getting to appointments outside of their home or community may be burdensome (19).

Lines 265-274

4. The authors state that the assessors were very experienced. However, some assessors had done as little as 1 assessment (assessors completed "between 1 and 460 assessments") before the pandemic and between "2 and 20 assessments" during the pandemic. Assessments of 1-2 patients is not enough to qualify as an experienced assessor. This has been changed to "most":

More importantly, it shows that most were experienced, active providers, Lines 287-288

5. Authors suggested that decreased hearing and use of PPE resulted in poor communication especially in older adults.

However, even before pandemic, decreased hearing was a significant issue in older adults, and assessors tended to write things down in order to ensure proper communication. This should not have been any different with the use of PPE, albeit I agree it could have made things more challenging. We agree that it is now more challenging and have clarified this:

Many people at the end of life have age-related hearing loss and other conditions that interfere with communication, so the mandatory use of masks made important communication even more challenging. Lines 245-247

6. Authors stated that "Another important theme was the anxiety about the spread of COVID-19 and about observance of the relevant public health rules and institutional policies.", and later add "Our participants varied in their comfort-level with this rule breaking, but all participants had experience with it."

The examples provided did not give example about "anxiety" of patients. Rather it was anxiety of the providers?, really this theme was not clear. We have made it clearer that this was the anxiety in providers:

Another important theme was the providers' anxiety about the spread of COVID-19 and about observance of the relevant public health rules and institutional policies. Line 210

7. Authors suggested that because transfers between institutions were not allowed, this "interfered with patients getting "palliative care." This requires more clarification. Palliative care is not usually dependent on the location of patient. Why couldn't the patient have received palliative care where they were? Was this truly a theme, or just 1-2 examples of patients not being able to transfer due to a personal choice or even due to specialist shortage in a community rather than the actual impact of a pandemic. Please clarify! We have clarified that this was a transfer to a palliative care unit

8. Overall, this is a very worthwhile study.

8a. However, I think the themes are not really about the MAID patient's experience (or even the experience of the caregivers/loved ones) but rather the provider

experience during the pandemic. The themes are about the observed experience of patients and we have made this clearer throughout the text.

8b. Also, I would ask that the authors review the themes they have come up with, as they do not make sense given the examples provided. We have reviewed these.

8c. Finally, the adaptations made by institutions are more likely to be the result of need for convenience, efficiency and reduced cost, rather than as suggested by the authors as adaptations to the impact the pandemic has had on MAID patients' experiences. Believe it or not, most institutions include at least some people who care about patients and their families.