Physician experiences with medical assistance in dying

Qualitative study in northwestern Ontario

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Abstract

Objective To explore physician experiences with medical assistance in dying (MAID).

Design An exploratory qualitative research approach using thematic analysis.

Setting Six communities in northwestern Ontario.

Participants Twenty-three physicians who perform, refer patients for, or are otherwise affected by MAID.

Methods One semistructured focus group and one-to-one interviews, transcribed and analyzed thematically.

Main findings The legislation of MAID added a layer of complexity to the work of physicians in northwestern Ontario, as MAID requires physician leadership, knowledge, time, and careful implementation. Four themes were identified from the interviews that unpacked this additional layer of complexity: relationships, motivation, time and resources, and getting others on board.

Conclusion The logistics of health care delivery in northwestern Ontario communities are complex and layered, which contributes to the burden of physicians as they work to provide MAID.

Editor's key points

- In focus groups and interviews involving 23 physicians in northwestern Ontario, participants expressed the importance of having medical assistance in dying (MAID) available to their patients. Some also stated their desire to ensure this option would be available for their own care at the end of life.
- The amount of time that MAID requires was a common concern among participants. The inequities people living in rural and remote areas of the province face in attempting to access care of any kind, including MAID, was another worry they shared.
- Physicians in northwestern Ontario have a strong desire to build the capacity for MAID in their region, with long-term sustainability a key aspect to be addressed. Affordable training and mentorship opportunities are needed in these communities to enhance physicians' capacity to deliver MAID in rural and remote areas.

Points de repère du rédacteur

- Dans le contexte de groupes de discussion et d'entrevues regroupant 23 médecins du Nord-Ouest ontarien, les participants ont mis en évidence l'importance de rendre accessible à leurs patients l'aide médicale à mourir (AMM). Certains ont aussi exprimé leur désir de faire en sorte que cette option leur soit accessible dans leurs propres soins en fin de vie.
- La quantité de temps requise pour recevoir l'AMM figurait parmi les préoccupations souvent soulevées par les participants. Les iniquités auxquelles font face les personnes vivant dans les régions rurales et éloignées de la province pour accéder aux soins, quels qu'ils soient, y compris l'AMM, comptaient aussi au nombre des inquiétudes exprimées.
- Les médecins du Nord-Ouest ontarien souhaitent vivement accroître les capacités nécessaires pour offrir l'AMM dans leur région, et la durabilité à long terme de ce service est un aspect important dont il faut tenir compte. Des occasions de formation et de mentorat abordables sont nécessaires dans ces communautés pour améliorer les capacités des médecins à administrer l'AMM dans les régions rurales et éloignées.

Expériences de médecins relatives à l'aide médicale à mourir

Étude qualitative dans le Nord-Ouest ontarien

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Résumé

Objectif Explorer les expériences des médecins relatives à l'aide médicale à mourir (AMM).

Type d'étude Une approche de recherche exploratoire qualitative à l'aide d'une analyse thématique.

Contexte Six communautés du Nord-Ouest ontarien.

Participants Un groupe de 23 médecins qui administrent l'AMM, qui demandent une consultation en AMM pour leurs patients ou qui sont autrement concernés.

Méthodes Des discussions semi-structurées et des entrevues individuelles, transcrites et analysées par thème.

Principales constatations La loi sur l'AMM ajoutait un degré de complexité au travail des médecins du Nord-Ouest ontarien, étant donné que l'AMM exige du leadership, des connaissances, du temps et une administration rigoureuse de la part des médecins. Quatre thèmes ont été cernés à partir des entrevues, qui ont révélé ce degré additionnel de complexité : les relations, la motivation, le temps et les ressources, et l'adhésion d'autres personnes.

Conclusion La logistique de la prestation des soins de santé dans le Nord-Ouest ontarien est complexe et compte de nombreux échelons, ce qui contribue au fardeau des médecins dans leur travail pour dispenser l'AMM.

Medical assistance in dying (MAID) became legally accessible across Canada in 2016, bringing substantial changes to the Canadian health care landscape. The history of its implementation spans more than 20 years and has been a contentious topic in Canadian health care and society at large. In 2015, in *Carter v Canada,* the Supreme Court of Canada determined that the criminalization of MAID was unconstitutional because it violated the Canadian Charter of Rights and Freedoms.[1] In response to the Supreme Court of Canada's ruling, the Government of Canada formally legalized MAID when Bill C-14 received royal assent on June 17, 2016.

Although the federal government laid out the criteria for access to MAID, the process for implementing MAID services was left to provincial and territorial health care systems to address.[2] Therefore, each province and territory has taken a different approach to rolling out the new service. In Ontario, for example, MAID programs are facilitated through participating hospitals and through the provincial care coordination program.[3]

The legalization of MAID meant physicians had to consider not only logistical changes in their practices but also their systems of values, beliefs, and professional identity, and they had to decide whether they would be able to contribute to this practice or participate actively in this new medical procedure.*[4] Canadian polling data from 2015 indicated 79% of the public favoured having the option of assisted death.[5] This is in stark contrast to the results of a survey of Canadian physicians conducted in 2014 that reported only 45% of respondents favoured legalizing MAID.[6] Before the legislation of MAID in Canada, 82% of surveyed physicians who treated patients with amyotrophic lateral sclerosis felt unprepared to deliver MAID and indicated a need for education and training in this area.[7] Additionally, the palliative care community expressed strong concerns with the change in legislation and asked for assurance that governments would address gaps and inconsistencies in access to palliative and end-of-life care and not solely prioritize the delivery of MAID.[8]

Rationale and purpose

Since the legalization of MAID in 2016, not enough time has passed, either historically or politically, to accumulate a large body of Canadian literature that examines the experiences of health care professionals who provide or facilitate access to MAID for patients. As the research on the practice of MAID in Canada is limited but emerging, a qualitative research methodology was employed as it is well suited to exploring phenomena that are context specific and evolving. The primary objective of this study was to explore physician experiences with MAID in northwestern Ontario. Specifically, we wanted to learn more about physician involvement with access, decision-making processes, and the provision of service. We were interested in hearing from physicians practising in northwestern Ontario—specialists and general practitioners alike, and regardless of whether they were active MAID providers—to learn if the change in legislation had affected them. Living in the north ourselves, we are aware of some of the challenges of health care delivery in this geographic area, including health care provider shortages, the lack of service availability, transportation issues, and the need for culturally appropriate care for a diverse population.[9] This study sought to increase our understanding of the additional challenges or rewards that the new MAID legislation might result in for physicians practising in northwestern Ontario.

About northwestern Ontario

The region of northwestern Ontario, spanning more than 526,000 km^2, constitutes the geographical area that sits north and west of Lake Superior and west of Hudson Bay and James Bay. Its western boundary is the province of Manitoba and its eastern limit is the town of Manitouwadge. Its largest urban centre is the city of Thunder Bay, with a population of 107,909.[10] There is one local health integration network—the North West LHIN—whose head office is in Thunder Bay. Northwestern Ontario is the province's most sparsely populated region, with 54% of the population living in the Thunder Bay district. Common in the region are small, remote First Nations communities, accessible only by air year round or by ice road in the winter.[11]

Methods

Study design

An exploratory, qualitative research approach with semi-structured focus groups and interviews was used to explore the perspectives of physicians who perform MAID, refer patients to this service, or are otherwise affected by MAID in communities across northwestern Ontario. Research ethics approval was received from Lakehead University in Thunder Bay and funding was provided by a small internal research development grant. Participants were recruited from across northwestern Ontario via social media posts (on Facebook and Twitter), which the researchers shared widely through their health care networks in northwestern Ontario. We also used both purposeful and snowball sampling to reach as many potential physician participants as possible. This method of recruitment was consistent with our iterative approach to analysis. All participants received an information letter and provided informed consent. No participants withdrew from the study.

*This study was conducted prior to the release of a policy introduced by the College of Physicians and Surgeons of Ontario that stipulates physicians have a duty to refer their patients for medical services regardless of whether they deem said services to contravene their moral or religious beliefs.[4]

The study used a social constructivist perspective to better understand how physicians in northwestern Ontario had been affected by the new MAID legislation. Constructivism is a theoretical framework focusing on both psychological and social ways of knowing.[12] Social constructivism focuses on how the development of knowledge has been created or determined within power, economic, social, and political forces.[13] The social constructivist framework allows for a focus on both the individual experience and the meaning they attribute to it alongside acknowledgment of the historical and social influences of systems, relationships, social interactions, legislation, and policy that were of interest to us and were reflected in the interview and focus group questions employed in this study.

Participants

Participants were 23 physicians (mean age 43 years, range 26 to 63). Eleven participants identified as female and 12 as male. They averaged 15 years in medical practice, with a range from 1 to 36 years. Fourteen participants identified as working in urban practices, in settings including family practice, as a hospitalist, in the emergency department, in palliative care, and in long-term care. Nine participants described their place of practice as rural and identified as rural generalists, working on reserve, in community or satellite clinics, or all of the above. Purposive recruitment ensured physicians from across northwestern Ontario and from diverse practice settings, as well as focused practices, were included.

Participants had varying experiences with MAID: 11 participants identified themselves as acting as both assessors and providers of MAID, 1 as an assessor only, 4 as providing referrals, and 7 without any direct experience with MAID. These 7 physicians were included in the study because they reported that their practices and the communities in which they work had been affected by the legislation and they expressed a desire to participate. The reported exposure to death in practice also varied, with a range between 2 and 250 patient deaths annually estimated by participants.

Data collection

To explore physicians' perspectives, a semistructured interview guide with open-ended questions was developed to address reaction to the legislation, impression of its impact on the communities they serve, access to MAID, delivery issues, and challenges and rewards experienced while incorporating MAID into the community health care delivery system. The interview guide was piloted with physicians and revised before implementation. Interview guidelines were used to facilitate discussions, but the interviews also followed an adaptive process to meet the needs of the participants and to capture the stories they wanted to share. Data were collected from a semistructured focus group (approximately 1 hour in length with 5 physicians) and from 18 semistructured interviews (ranging from 17 to 48 minutes in length). Both members of the research team participated in the focus groups and conducted the interviews. Clearly identifying as nonphysicians, the researchers were transparent about their previous work in palliative care. All participants were aware that both researchers live in northwestern Ontario and work in an academic research setting.

Data analysis

The interviews and focus group were digitally recorded with the consent of participants, transcribed verbatim using Dragon software, and manually reviewed for accuracy. Thematic analysis with an inductive approach,[14] a process involving prolonged engagement with the data resulting in the abstraction of themes from the raw data, was used. This allowed the researchers to interpret themes extracted from the data and to identify and compare experiences. The researchers performed an initial scan of the data to generate initial codes. In the second phase, both researchers met to identify themes through collaborative analysis. We used constant comparison to guide coding, categorizing, and theoretical sampling. In the final analysis phase, both researchers reread the data and extracted samples that best illustrated the final themes. Both authors reviewed all coding to ensure there was agreement and accuracy within the coding process and thematic analysis to promote data trustworthiness. Through this process and analysis, the themes outlined below emerged. Thematic analysis was guided by Braun et al's 15-point checklist of criteria for good thematic analysis.[14]

Findings

The legislation of MAID added a layer of complexity to the work of physicians in northwestern Ontario, as MAID is another intervention requiring physician leadership, knowledge, time, and careful implementation. Four themes were identified from the interviews that unpacked this additional layer of complexity: relationships, motivation, time and resources, and getting others on board.

Relationships

Participants shared that they were cognizant of how the option of MAID at the end of life affected their therapeutic relationships with their patients. A number of rural physicians also discussed how it had touched them in particular with patients with whom they had long-standing relationships:

> The experience of ending the life of someone for whom you've been providing care for 20 years is different than

> the specialist coming in for 15 minutes and administering a med. I think until you've done it, clinicians carry a fear that it's going to feel horrible and be horrible, and if you are already overworked and burned out, even if cognitively you can wrap your head around the procedure, you may not be able to wrap your heart around what that's going to feel like for you and whether you'll be able to cope with that.

> This is a very small community and there are people that I've known for years and there are people where I'm going to see their families over and over again .... [Rural] medicine is like that to begin with, but when you're talking about helping somebody end their life, it's even more [so].

For the study participants, the decision to become MAID providers affected not only their relationships with their patients but also those with their own families and social circles. Physicians noted what they had reflected on before deciding to become MAID providers, including the role of family and other support available to them in that process:

> I also went through a long process with my family .... I wanted to make sure my [partner], who is my main source of support, would be okay with this, too. I don't think, you know, it's not back in the day when people would picket outside [a doctor's] house with anti-abortion signs but, you know, with it being a small town, wanting to make sure that he was on board and he felt comfortable ... and he's been amazing.

> I know the difference, I know I why I'm doing it, I'm not murdering someone ... but you need a really good social support network because you just don't know ... what's going to happen ... or what someone might say to you .... [It] definitely did sit with me, it definitely did keep me awake at night, but as time went on ... seeing how happy this woman was that I could give her MAID, it was worth it, beyond worth it.

Motivation

An altruistic motivation to participate in MAID was voiced by many physicians in the region, including one who felt that while the Ontario Medical Association initially did not make compensation a priority, there would always be physicians willing to provide the service, regardless:

> It's another thing that I think they (the ministry) see on the backs of family physicians who are generally a pretty quiet group, right? If they were asking orthopedic surgeons to do this, there might be more noise.

Other participants spoke of the need for access to MAID in their communities and recognized that this might be a medical intervention that they might want to access one day, too; therefore, they need to lay the groundwork now:

> I would want the option. If I would want the option, it wouldn't be fair for others to not have the option—if they don't have the option, I'm not gonna get the option, so let's get at it.

Time and resources

A common concern voiced by participants was the amount of time that MAID requires, as does most end-of-life care. This included challenges related to work-life balance and the demands of taking on another responsibility:

> I think for me personally some of the hard parts are just finding the time. It's labour-intensive, like palliative care in general ... and you want to be present for the patient and have time for them and take in their own experience. And I'm kind of doing this for the community, so it's in addition to my practice. I have small children, so it's kind of trying to balance that workload. We all do it as kind of a side practice.

> This is one more thing that physicians now have to figure out .... When physicians are really busy and feeling overwhelmed and you bring something new to them, whether it be medical cannabis or MAID, the thought of adding a new skill set and new knowledge requirements is just overwhelming for a lot of rural physicians.

A recurrent theme in participant interviews involved issues related to resources in the region and the geographic inequities experienced in northwestern Ontario, including the lack of community home health care and nursing support. Physicians shared that they were concerned that a lack of resources available to communities for patients at the end of life might influence the request for MAID:

> My concern is that if people are in a rural community or remote from the city ... that they may be accessing MAID when they could have been helped in other ways.

> There's clearly not enough palliative care available, and I worry more here than I did in Toronto ... [that] people are not accessing palliative care .... So, then I'm worried that MAID becomes a bit ... of an easier way out.

Further inequities surfaced, as people are aware that there are certain specialty services that have never been available in rural and remote parts of northwestern Ontario. Several physicians across the region stated that their patients were surprised to learn that they could even ask their family physicians for MAID:

> And sometimes people have been surprised to know they can access it here .... I often have met with some

> relief about that. I'm glad to know that it is something we can do here.

The social determinants of health play a role in the perception and uptake of MAID in northwestern Ontario, as well. In some Indigenous communities, where patients would most likely have to travel to access the service, a physician in a remote community described MAID as being relatively low on their practice radar:

> I have 25 new cases of hepatitis C in a community of 550 since I started, so my energies are focused on things other than MAID for the time being.

Getting others on board

Many participants in this study expressed a strong desire to build the capacity for MAID in their communities. However, physicians were unsure about how this would manifest, and even those willing to go to great lengths to ensure MAID was available feared for the long-term sustainability of this service:

> Interestingly, ... in [our town], I don't know if there is anybody who would be kind of a lead physician. We're kind of behind the eight ball on this; we still really haven't got well-sorted-out processes.

> [If] we want to increase capacity ... [we need to expand beyond] those early adopters who are willing to engage because they believe it's the right thing to do.

Participants also recognized some of the challenges created by physicians being able to conscientiously object to the intervention and the impact that could have in smaller communities, such as one person ending up as the sole provider of this service:

> The decision to allow people to opt out has been a bit hard on us because it then falls to the people who aren't opting out.

> Knowing that I'm the only one in [town] who can provide this or is willing to provide this for a patient, I had one patient who had requested MAID but hadn't picked a date yet, and we'd gone through the process but I was taking a holiday for a month and I was distressed on both his and my behalf that perhaps I wouldn't be available when he needed this done.

One of the things that helps build capacity for MAID in northern communities appears to be the informal mentorship that physicians are offering one another. Physicians in this study recognized that collegial mentorship in MAID provision plays a vital role in recruitment and retention. Several providers expressed their reliance on older practitioners who were willing to take the first steps and their appreciation of the leadership role taken on by more experienced physicians:

> I feel like the older docs were perhaps more willing to take the first steps and provide a bit more [of a] gentle footing for us younger doctors to kind of make our way through .... So, that was really helpful.

Those willing to pursue MAID provision shared the sentiment that without someone to demonstrate expectations and practices, the information and education resources from the governing bodies would have been grossly inadequate. As one provider suggested:

> I have to say that without their support in a mentorship role, it wouldn't have been enough .... We send out calls that there are people willing to mentor, so if you want to get involved [there is support].

However, there was concern that those new to a community might feel intimidated, not knowing whom to contact or with whom to even broach the topic of mentorship; therefore, the need for a more formalized approach to mentorship was stated:

> I think a lot of physicians are still very anxious about it .... I think formalizing [the mentorship role] just makes it that much easier to do.

Discussion

This study provides an initial understanding of the experiences physicians working in northwestern Ontario have had with MAID. Overall, physician participants shared that they found the provision of MAID to be rewarding and an intervention they wished to have access to themselves and for their families at the end of their lives,[15-18] regardless of the challenges. This was among the primarily altruistic motivations given by early adopters to provide MAID in addition to their already busy practices and at rates of financial compensation that failed to reflect the time and energy required.[17,18]

Physicians and the patients in their care are now faced with the challenge of addressing this unprecedented (in Canada) health care procedure,[19] particularly as its adoption and implementation vary in terms of pace and practice among provinces and territories.[2] Not surprisingly, physicians in this study reported frustration with the lack of clarity around MAID practices in Canada described previously.[20] As such, sensitivity to local communities' needs is essential to the creation and adaptation of systems that meet the needs of both patients and providers.[19,21]

For physicians in northwestern Ontario, many issues surrounding MAID mirror those experienced across the country and beyond.[15-18,21-24] However, in northwestern

Ontario, as in other remote parts of Canada, the need for locally scaled systems is pertinent due to geographic location and vastness of size.[25,26] Specifically, physicians in northwestern Ontario who are currently providing MAID or assessing patients for MAID, or who are contemplating doing so, are often burdened with additional issues derived from challenges that are unique to rural and remote areas such as access to services, isolation, capacity, and sustainability. This study reinforces the need to continue to address these general challenges found in the literature[15-18,21-24] and encourages the development of geographically appropriate systems in order to provide high-quality palliative and end-of-life services in rural and remote areas of Ontario.[25,26]

Further, the provision of MAID contributed to an already laden workload, thus it often took an emotional, physical, and psychosocial toll. This reinforced the need for collegiality and peer support in the workplace that is supported by earlier studies,[17,22-24] which included evidence that negative experiences resulted when colleagues differed in their perspectives and clashes ensued.[23,24] Participants in this study were clear in identifying that collegial mentorship in MAID provision is essential to the recruitment and retention of providers and the sustainability of the service.

Physicians also stressed that the work was time-consuming, above and beyond the usual parameters of their primary practices, which had also been noted in earlier research.[24] The time and energy required also created feelings of isolation, loneliness, and a sense of loss, as echoed in other studies.[22,23] This was particularly felt where physicians were among the few, or even the sole, providers of MAID in a community, which was more often the case in this study than in others.[17,26]

Although issues of travel and scarcity of MAID providers in rural areas were prevalent across the literature,[17,22,23] they in no way were directly comparable with the extensive distances and isolating environments experienced by the physicians in this study. While other studies have explored the use of telemedicine platforms for MAID in rural and remote areas,[26] the physicians in this study emphasized the importance of being present in their relationships with patients, which might prevent this mode of MAID delivery being useful. Thus, the geographic location and vast size of northwestern Ontario are persistent challenges acknowledged in this study and in previous research[17,22-24] when recognizing the vital role of mentorship in the recruitment and retention of physicians to provide MAID. Participants in this research emphasized the necessity of in situ opportunities for mentorship and education.

Recommendations

The findings from this study align with suggestions made in aforementioned studies and scoping reviews[17,23] that MAID training needs to be included in medical education curricula. Additionally, our findings support that practising physicians need access to affordable training and mentorship in their own communities to develop their capacity to provide this medical intervention for patients at the end of life across northwestern Ontario.

Limitations

Despite the contributions of this work to the research and health care delivery landscape of northwestern Ontario, there are limitations to note. No participants identified as conscientious objectors in this study, and we were unable to get representation from all the communities we attempted to reach. Further studies with conscientious objectors and additional community representation might offer differing perspectives. Additionally, there is limited transferability of these findings to other Canadian communities due to the unique qualities of northwestern Ontario. As with all qualitative research, we are unable to generalize the findings since the sampling strategy was purposive rather than random, and participants were self-selecting.

Conclusion

This study highlights that the provision of MAID is a rewarding and challenging experience for physicians in northwestern Ontario. The logistics of health care delivery in northwestern Ontario communities are complex and layered, which contributes to physician experiences as they work to provide MAID. There is a need to understand the physician experience and address the current challenges of effective implementation of MAID in order to retain current and recruit new providers of MAID and to ensure that this option is available for northern Ontarians at the end of life.

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Contributors

Both authors contributed to the concept and design of the study; to data gathering, analysis, and interpretation; and to preparing the manuscript for submission.

Competing interests

None declared

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