MAiD in Southern Alberta

REPORT OF FINDINGS

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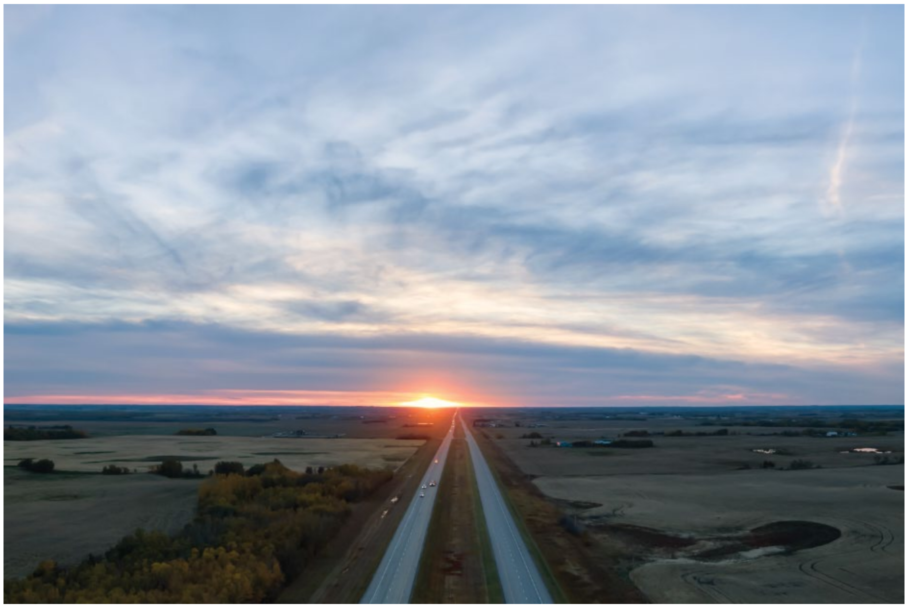

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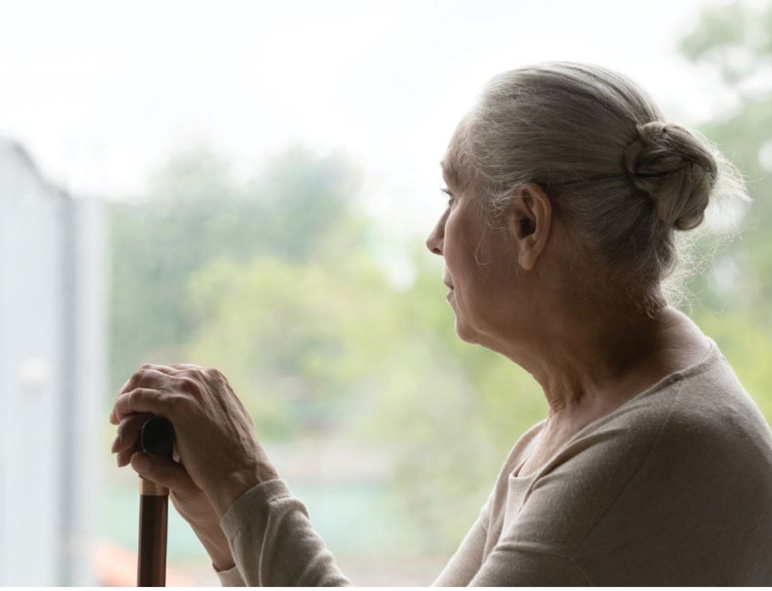
Executive Summary



In this report, we outline findings from a SSHRC Insight Development project on Medical Assistance in Dying (MAiD) in rural Southern Alberta. Although there are many definitions of “rural,” this project operationalizes the concept in a broad way. In the eyes of Alberta Health Services, all of AHS’ South Zone of the province is considered rural, so we collected data from a range of South Zone communities (without exclusion based on factors such as population size or postal code).

Our main objective was to hear from South Zone residents (i.e., related health care professionals, patients pursuing MAiD, and their family members) about their lived experiences of the MAiD inquiry, provision, and caring processes. This work enabled us to situate ethical and procedural debates about MAiD within a rural context and avoid stereotypical assumptions about rurality or rural homogeneity, as well as about MAiD itself.

Before conducting interviews, our team performed a review of MAiD legislation and policy to better understand how rural considerations are included or omitted from them. This article is available (without cost) through the following link: https://doi.org/10.1016/j.jrurstud.2022.09.011.

We interviewed 29 participants (8 nurses, 1 nurse practitioner, 7 physicians, 2 clinical ethicists, 8 family members, and 3 patients). We asked them about their experiences with MAiD, related challenges, aspects of the service that are working well, rural-specific considerations, implications of the passage of Bill C-7, and ongoing ethical and practical issues.

By virtue of our inclusion criteria (i.e., that participants had to have experience with MAiD), our sample was generally supportive of the practice. However, our participants expressed a broad range of experiences and perspectives on the topic, which included some critical assessments of current policies and practices. We heard about the complex nature of MAiD itself, the benefits and limitations of the rural context, notable systemic issues, and ethical issues of concern. We also heard about ongoing tensions between autonomy and paternalism, and between transparency and confidentiality.

As several participants suggested, end of life is both profoundly universal and deeply personal. It can force difficult conversations about deeply held values and beliefs, reckoning with mortality, and engaging with family dynamics and health care systems. Our participants openly and graciously shared their reflections on these complicated experiences. In what follows, we outline some of the key concerns from the academic literature, briefly describe our methods for data collection and analysis, share key findings, and offer considerations for policy and practice.

Background

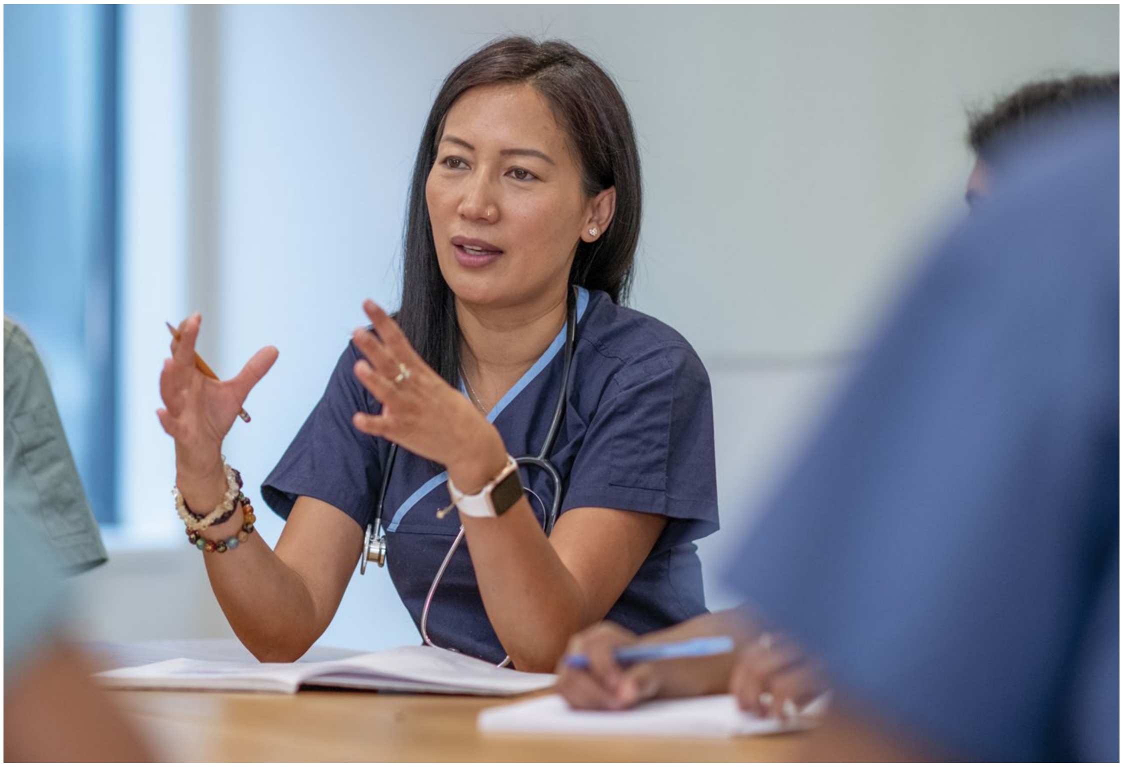
In a 2015 ruling, the Supreme Court of Canada unanimously voted that the prohibition on assisted death in the Criminal Code was unconstitutional (*Carter v. Canada*, 2015). This led to Parliament passing Bill C-14 in 2016, amending the Criminal Code to allow legal exemptions for MAiD. Since its passage, MAiD usage has increased every year, with a total of 10,064 MAID provisions in 2021 alone, accounting for 3.3% of all deaths in Canada (Health Canada, 2022).

In Bill C-14, the requirement that one's natural death be reasonably foreseeable was considered controversial. Some MAiD advocates argued that this requirement was too ambiguous and restrictive. In 2019, the reasonable foreseeability of natural death criterion was challenged in a Québec court and declared unconstitutional (*Truchon v Canada*). As a result, in 2021 the federal government passed Bill C-7, which made several amendments to Bill C-14. Most notably, MAiD was now accessible for individuals experiencing grievous and irremediable suffering whose natural death was not reasonably foreseeable. The legislation is likely to continue to evolve in coming years. For instance, the prohibition on MAiD for those whose sole underlying condition is a mental illness was set to expire early 2023 and the federal government has delayed this amendment until 2024.

Although public polling suggests that the majority of Canadians support MAiD, their opinions about the service are nuanced and complex (Pennings & Reid, 2020). There continues to be stigma, taboo, logistical and procedural challenges, as well as ethical and equity concerns about the practice. Debates about MAiD are also not uniform across Canada. There are some significant differences in MAiD processes and practices between provinces and territories (Silvius, Memon, & Arain, 2019). Similarly, data from Alberta Health Services (AHS) South Zone (2019) suggest intraprovincial differences between urban and rural communities, particularly related to knowledge and attitudes about MAiD.

Within discussions about MAiD, very little attention has been paid to rural parts of the country. There is no singular, agreed upon definition of rural (Kulig & Williams, 2011), but the concept often includes a combination of geography, culture, population size or density, and qualitative experience (Chalmers & Joseph, 2006). Herron and Skinner (2018) recommend a relational approach to studying rural health because it acknowledges that "people, ideas, and goods flow between urban and rural settings, connecting people and places in diverse ways and across a range of scales" (p. 268). This concept of the "relational rural" is nuanced, flexible, and reflective of our research context.

Given that rurality is a significant and often overlooked determinant of health (Smith et al., 2008), it is important to examine the distinct conditions for MAiD in rural settings. For instance, there is concern that in rural settings where there is often more limited health service provision, residents might feel compelled to use MAiD as a default option. Some scholars have suggested that MAiD may be seen as the "perfect solution for rural and remote patients who want a home death, but are unable to find sufficient palliative care in their context" (Pesut & Thorne, 2019). Others have called for caution to ensure that geographically isolated individuals are not placed in a position where MAiD will be seen as their only "source of respite from end-stage disease" (Collins & Leier, 2017).



MAiD may also present distinct ethical challenges in small communities where there is less privacy or anonymity, and where people may be concerned about stigma associated with requesting, providing, or receiving MAiD (Mah, 2016). These practices are further complicated by the fact that many rural health care professionals are highly visible in their communities and know their patients outside of the professional context (Simpson & McDonald, 2017). These longstanding relationships with patients may compound feelings of duty and/or grief. At the same time, rural settings may provide unique benefits. These rural strengths have yet to be explored in MAiD-related research.

There is a dearth of literature regarding rural residents' experiences of MAiD. Some scholars have noted that MAiD is often depicted via "one-dimensional stereotypes of health-care providers and patients as heroically conquering suffering, or caricatures of critics as religious dogmatists who lack compassion" (Pesut & Thorne, 2019). Both representations lack the nuance that would improve micro level discussions and macro level decision-making. To better understand the evolving landscape of MAiD in Southern Alberta, we conducted the study described in the following section.

Method

We used a qualitative exploratory design to better understand experiences of MAiD in Southern Alberta. We received ethics approval for this research from the University of Alberta Research Ethics Office (Protocol number 00103469).

Data collection took place between September 2021 and April 2022. We recruited participants from several categories: physicians and nurse practitioners who provide MAiD assessments and/or provisions, clinical ethicists, nurses who provide care for MAiD patients, family members of people who have received MAiD, and patients who have applied for MAiD. We recruited our participants with the assistance of key contacts in Alberta Health Services.

We conducted semi-structured interviews with 29 participants (8 nurses, 1 nurse practitioner, 7 physicians, 2 clinical ethicists, 8 family members, and 3 patients) and conducted a demographic survey with each participant. We conducted the interviews via Zoom and over the telephone. We asked about experiences with MAiD, related challenges, aspects of the service that are working well, rural-specific considerations, implications of the passage of Bill C-7, and ongoing ethical and practical issues.

The interviews were digitally recorded and lasted between 35-75 minutes. The transcribed interviews were coded and critically analyzed using Braun and Clarke's (2006; 2022) approach to thematic analysis. In the following section, we describe our key findings.

Key research questions

What are the experiences of those involved with MAiD in Southern Alberta?

How are the ethical and procedural issues surrounding MAiD experienced by those living and working in this region?

What issues or experiences are distinct to rural settings?

Findings

Broadly, our participants described MAiD as somewhat of a paradox. For instance, they stated that MAiD is like any other health care service and should be treated as such (e.g., a lack of stigma, professionalism between colleagues, adequate funding, etc.) and it is simultaneously unlike any other health service (because it requires distinct supports, approaches, and considerations, and is client-driven). Although the process was predominantly described as peaceful, beautiful, and person-centred, it was also recognized for its lingering taboos and political and ethical tensions. Similarly, participants expressed desire for standardization and consistency in the process, but also for the flexibility to individualize care as needed. These complexities illustrate the dynamic nature of assisted dying.

Our participants also reinforced the significance of lived experience when it comes to discussions about MAiD. We were told several times that an individual may think they know how they would feel or what they would want when it comes to their involvement with MAiD, but until they have experience with complex end-of life decision-making, they cannot really know how they will react and feel about MAiD. Health care providers shared that their degree of involvement with MAiD varied and was influenced by a number of factors. Like families and patients, they too did not really know how they would react in any given situation.

Overall, our findings confirmed and extended the themes from the existing literature and highlighted experiences specific to the Alberta context. Key themes include: the significance of place and the specifics of Southern Alberta, the realities of the relational rural, and the challenges associated with working with limited resources.

1.

Place matters: The specifics of Southern Alberta

(a.) The reputation and culture of the region influences expectations and experiences.

Most participants spoke about the ways in which the specifics of Southern Alberta informed their assumptions, expectations, and experiences related to MAiD. For instance, some participants referenced the region's socio-cultural reputation for being very Christian and Conservative These participants contextualized their experiences within this setting, acknowledging that they anticipated community pushback or opposition to the MAiD program because of the region's culture and reputation.

> *"Southern Alberta is… I call it the 'bible belt' of Alberta. So, there's a lot of extremely religious groups down here… I think that if people are choosing to go the MAiD route but they're part of a community that doesn't support that, then that patient or that family have the potential to be ostracized from their communities. So, it does make it more of a challenge."*
> *(Nurse 2)*

"I wasn't sure if I was emotionally ready [to be involved with the MAiD program]...I was worried. People told me [that my] kid won't get invited to birthday parties, stuff like that. So, yeah, it was nerve-wracking for sure."
(Physician 1)

In some ways, the expectations and stereotypes about the region were confirmed. For instance, some participants indicated that conscientious objection is high in the region. Similarly, several participants told us about experiencing unprofessional comments from colleagues who were unsupportive of MAiD, leaders within the health authority who actively worked against the program, fearing reprisal within their profession, and feeling like they needed to keep their involvement with MAiD a secret.

"I was agreeable to do the provision but I was told that I couldn't because some of the staff might change their opinion and their respect of me if they knew that I did MAiD. And I struggled with this."
(Nurse 4)

"I don't want other people, for example, my colleagues or my patients who are not involved in MAiD, to know that I do it, because I feel that that could be putting my reputation at risk, my future career options at risk."
(Nurse 6)

At the same time, we noted that demographic characteristics regarding religious and political affiliation are not necessarily reflective of an individual's views about MAiD. For instance, in our sample of people who have direct experience with MAiD, 16 participants identified as having no religious affiliation, 4 identified as Christian, 1 as Roman Catholic, 1 as Anglican, 1 as Jewish, and 6 as spiritual. Fourteen participants identified as having no federal political party affiliation, 6 identified as Liberal, 6 as Conservative, 2 as New Democrats, and 1 preferred not to disclose their political affiliation. The demographic data suggest that support for MAiD is not neatly divided along political or religious lines and remind us to avoid making sweeping assumptions.

Similarly, some participants' experiences challenged the stereotypes about the region. Several participants claimed that the backlash that they had anticipated never came to fruition and that community members often "agreed to disagree" rather than adopt a polarized stance on the issue (Nurse 4). Several of these participants attributed this to what we call an ethos of rural independence, in which autonomy and free choice trump differences of opinion about MAiD. This was seen as a more libertarian approach to the service and placed emphasis on people being able to make their own choices:

"I was raised in a very conservative religious background... it's my personal belief that it's not my place to agree or disagree, like or dislike, influence – tell you yes or no, that you should or shouldn't do this. It's my place to respect your decision, your freedom of choice. So, that's why I don't have an issue with my upbringing being part of the MAiD program, because this isn't about me and my beliefs. This is about allowing a person to choose their destiny, their lifestyle. Because, again, I don't have to like it, I don't have to agree with it, but I dang well need to respect your personal decisions"
(Nurse 1)

(b.) The rural landscape itself was significant for many participants.

Several participants suggested that their rural roots and personal histories with ranching informed their decisions to become involved with the MAiD program. They indicated that the program reflected similar values about alleviating suffering for living beings at the end of their lives:

Something I hear from patients all the time, and it's how I feel too, I grew up on a farm. I grew up on a ranch. And patients tell me this all the time. They say, 'We wouldn't treat our animals this way. Like, we've been putting down animals, in humane ways, that we care about, for, I don't know how long, right?' And, you know, that was something I grew up on the farm seeing, and I will never forget, I accidentally ran over a cat one time, in the farm, and I was devastated. And my dad came out with the gun and was like 'this is sad and it's scary and I know you're young, but this animal is not allowed to suffer.' And so that was just something we were kind of used to, and animals, cows, and things that were not going to recover. We were taught that that's a way to be humane, and to try not to let things suffer."
(Physician 7)

My father always said we were more humane to our animals than we are to each other. So that's why it was such a beauty that he got to do what he wanted to do [receive MAiD]."
(Family Member 1)

We also heard that the rural landscape was significant. A number of patients wanted to die on their land and/or with their animals present.

"One farmer had [MAiD] out on his field. Like, he had it all set up on a little hill, you know, where he could see his land and all of that, and that's where he wanted to pass."
(Ethicist 2)

"I don't want to be on machines. I don't want to be in a respite home. I don't want to be in a nursing home. Those are all bad things. And it's different in rural than urban settings. I've lived on the end of a dirt road for most of life… when I pass away there's going to be no gravesite, we're going to take my horse and he is going to haul my fat ass and the ashes from one of my favourite dogs and we're going to go west of town and they're going to spread them in the wind."
(Patient 1)

Finding #1 Implications & Considerations

In short, context matters. Our findings demonstrate the significance of place when it comes to MAiD. The local culture(s), the regional geography, dominant industries (such as ranching), and connection to the rural landscape itself all informed our participants' thoughts and experiences of MAiD in Southern Alberta. For instance, several participants noted that conscientious objection is high in this region. The high rate of conscientious objection has implications for access to MAiD service provision, access to information about the program, and the stigma that surrounds it. There is a need to ensure that rural patients seeking MAiD can access related information and care (knowing that strategies for information-sharing and service delivery may need to look different in particular rural and remote contexts). We also saw that concerns over reprisal or harm to one's reputation factored into the decision-making of health care professionals and caused them stress and undue burden. Efforts should be made to ensure that supportive providers do not experience professional fallout because of their participation in the MAiD program, and also that abstaining providers are protected from pressure to participate or to feel guilty as a result of their conscientious objection. Targeted education about MAiD in rural settings and guidance for navigating challenging conversations about the practice could help to de-stigmatize it and support all care providers.

Our findings challenge the assumption that support for or opposition to MAiD fall neatly along partisan or religious lines. As a result, it is important to avoid making assumptions about people's views on MAiD based on these affiliations and/or regional demographics. People's support for or opposition to MAiD can be context-specific, situational, and fluid. Distinct to the Southern Alberta context, we saw that a value of autonomy informed many participants' thinking on the topic. Rural residents' views are, of course, heterogenous, but an understanding and consideration of this ethos of rural independence may be useful in navigating discussions about MAiD, related health promotion or educational efforts, and/or service delivery. A less polarized approach to this issue is likely to generate more compassionate and more productive outcomes for everyone involved.

Lastly, scholarship about the concept of a "good rural death" often stresses the importance of not displacing individuals from their homes or their land. In fact, many rural residents express strong preferences for ensuring that death and the preceding care occur within their community (Wilson et al., 2009; Rainsford et al., 2018). Some have noted that the displacement of seniors for the purposes of obtaining care can result in feelings of loneliness and increasingly negative prognoses (Wilson et al., 2009). Our findings demonstrate that given the option to have MAiD-related care and the MAiD provision itself performed in a patient's home or home community, the value of a "good rural death" was supported. Providing at-home MAiD-related care or provisions can be onerous for rural health professionals who do this work off the side of their desks or must travel great distances to support a widely dispersed population. This is especially true in regions where there are few MAiD providers. MAiD programs should continue to be attentive to both the burden of travel (resourcing it appropriately and considering it when it comes to scheduling) as well as the considerable benefits of at-home provision.

2.

The realities of the relational rural

(a.) Dual roles and long-standing histories can be an asset for rural care provision.

In the rural context, personal and professional lives often intersect. In our findings, personal connections and dual relationships between health care providers and patients were not just described as an inevitable part of rural medicine, but also as an important asset for MAiD provision. Our participants noted multiple benefits of knowing the patient or health care provider during such an intimate process. For some physicians, having a longstanding history with the patient and knowing their story helped them to feel clarity and conviction when assessing if someone was a suitable candidate for MAiD or providing the service for them. Several physicians described MAiD as part of the “cradle to the grave care” that they offer rural residents and explained the significance of this relationship.

"I am from a town of a thousand people, and it's only two hours from here. So, I know a lot of people around here... and I will say, if you work rural medicine, you deal with dual role relationships. And if you don't know how to deal with that, you've got a problem. And so that has not escaped me in MAiD. I have provided for at least a small handful of people I know. I have assessed people that I know. I am always cautious to say that there's other assessors we will find, and I mean, I would never show up as a provider without being involved in that situation, but it's interesting. They want it. The patients want it... And, I mean, that's one of the joys about real cradle-to-grave care... It's not easy, I think, for some physicians, but it's never easy when our patients go, you know? So I think it is one of the things that can be worked around. I know I have seen family physicians who aren't part of the MAiD program per se, but will step up for their patients, and that, I think, is one of the strengths of the rural experience."
(Physician 7)

"Whether it's a MAID death or not, in our facility, the person who has died is usually someone we've looked after. This one man, he was one of my first patients as a grad nurse. I had looked after him off and on for the better part of a decade. I liked it. I like having that rapport with patients before and I like having that history with them so hopefully they're comfortable with me. It's not just a stranger showing up on their last day on this planet. The last [provision] that I did was my doctor's father. My physician's son taught my son swimming lessons and I did [social activity] with their daughter. It was very emotional, but I was really glad I could be there for them because I have relationships with four people in the family. It was nice that they knew me. I wasn't a stranger."
(Nurse 8)

(b.) Limited privacy and heightened visibility can be a challenge for MAiD care in rural communities.

There is more visibility and less anonymity in rural settings and that presents distinct considerations. For instance, we heard that stigma was a great concern for health care professionals, patients, and their family members. This was something that kept several physicians and nurses from feeling as though they could be open about their participation in the MAiD program.

Some physicians were worried about potential harassment that they or their families might receive. For a few physicians, these fears were compounded because of their gender or sexual orientation and they expressed not feeling safe being known as a MAiD provider in a small, conservative, religious community. Others expressed concern that if it were known that they provided MAiD, community members may lose trust in them, they may become ostracized by colleagues, and it may do irreparable damage to their professional reputations and personal lives.
Several nurses claimed that being casually involved with the MAiD program felt like being a member of a secret society:

"I mean I'm open about it but it's definitely not something I advertise... you kind of want to be a little bit careful. It's not because I'm embarrassed. It's just I don't want people to think of me differently or treat me differently or judge or question the care that I give my patients because I do MAiD. Right? Like just because I do MAiD doesn't mean I don't want someone to have palliative care or I don't want them to have active chemo care, right? It's what the patient wants."
(Nurse 4)

This fear of small town stigma may also complicate decisions around when and how medical professionals broach the topic of MAiD with their patients. Physicians and nurses must balance a) the duty to present patients with all available options with b) ensuring that they are never seen as inducing, persuading, or convincing patients to pursue MAiD. We heard that this can be challenging:

"[One of] the bigger struggles that I see here is when do you introduce it? Do you only talk about it if the patient brings it up, or do you actually bring it up when you're talking about palliative care? And I bring it up very carefully when I'm talking about palliative care..."
(Nurse 4)

Family members were also aware of the risks that rural health professionals undertake by participating in the MAiD program. Several of them told us about how they too sought to protect their care providers' anonymity:

> *"I think there's only three doctors involved and I know it's a risk to their practice... They're willing to take that risk which I really admire... It's divisive in some ways. And we were careful who we let know and they don't know who [the provider] was that assisted us, and we tried to keep it that way for their benefit."*
> *(Family Member 8)*

Similarly, some family members expressed that they were reluctant to tell members of their family, community, or faith group that their relative had received a medically assisted death. This introduced challenging situations such as bringing the MAiD provision team into a health care setting without other patients or staff knowing about it, decisions about whether the MAiD team would be mentioned in an obituary, and not being able to acknowledge how these family members knew particular health care providers when encountering them in the community. In some cases, care providers were faced with a tension:

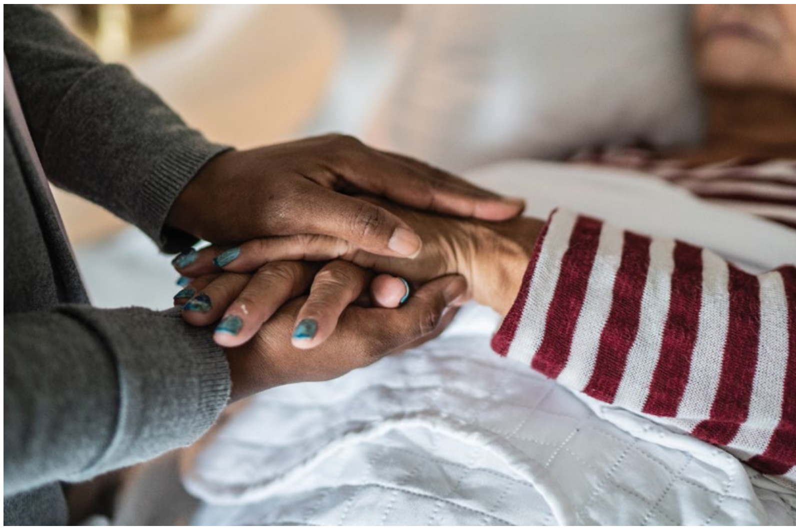
> *"Staff had to really balance transparency with confidentiality... One of those transparency pieces, very clearly from the government, was accurate recording, so that there was nothing secret... [But] we've had patients who have said, 'I don't want my family to know.' But they're going to find out what the cause of death was; the death certificate is very clear."*
> *(Ethicist 2)*

The fear of stigma also kept some family members from participating in grief support groups. They did not want to reveal their loved one's secret and/or felt that their grief would not be understood or supported in the same way as someone who was grieving a non-MAiD death.

(c.) Rural care is seen as preferable by patients and family members.

In interviews with patients and family members, we heard a perception that in larger cities, it is more likely that you will be treated as a number in the health care system; that they may have more services and better technology but not the same type of personalized care. There was value in being known.

> *"The doctor was amazing. I mean she made house calls for a week, right. Every night she came to the house to see my mum, to sit with me. You're not going to get that in the city. So, I'll take rural."*
> *(Family Member 1)*
>
> *"We're very fortunate in [small town] because we've got a really good medical team here. So, there's a doctor shortage, but there's nothing like the doctor shortage in [nearby city]. I have a family physician and if I didn't have a family physician, there's a 90% chance I would not be here today... I have a tonne of respect for him, he saved my life. So, for every day I've had in the last year and a bit, that's because of him and because of our health system. So, for me it's kind of special [that he will be the MAiD provider]... he knows the community, he knows who I am, he knows who [wife] is. You know, it's kind of like – if you've been to a funeral where the funeral director does the talk and, you know, he's never met the person and then starts saying things and misspells names or mispronounces names and all that kind of stuff... It's a very different experience."*
> *(Patient 1)*



Finding #2 Implications & Considerations

Dual roles are often framed in rural health scholarship as a potential ethical challenge to be navigated. Simpson and McDonald (2017) point out that in rural settings, professional and social relationships may have an intensity and visibility unlike those in urban centres. Decisions to participate in or abstain from MAiD are informed by relationships in the community and have implications for those relationships and others (Pesut et al., 2019). Our findings both confirmed and challenged traditional thinking about dual roles. Our findings suggest that in the context of rural MAiD provision, dual roles do indeed require careful navigation, but they can also be a tremendous asset that leverages the relational context and supports person-centred care. Policies and guidelines should therefore be sensitive to this rural context. Blanket opposition to dual roles due to concern over conflicts of interest may not always be feasible in small towns. As we heard, avoidance of dual roles may also create harm, as MAiD patients appear to derive comfort and benefit from knowing and being known by their providers and care team. Such relationships can also aid MAiD assessors regarding some of the complexities that may be involved in determinations of MAiD eligibility (i.e., more intimate knowledge of a patient's history and life context).

The extant literature also included considerations about the potential stigma associated with MAiD in rural communities (Mah, 2016). This concern was expressed by participants of each group in our study (i.e., patients, family members, and health care professionals) and was certainly an element of their experience. These findings extend our understanding of this stigma in two ways. First, we learned that the widespread fear of stigma contributed to the creation of a "secret society," whereby health care workers felt the need to keep their participation in MAiD private. This secrecy only reinforces the idea that MAiD is taboo. This is problematic for two reasons. It continues to stigmatize medical providers who are involved with the MAiD program, as well as the patients and families for whom they provide care. Additionally, such secrecy can undermine accountability and transparency and prevent awareness of MAiD's risks and benefits. Greater understanding and consistency is required in terms of how privacy and transparency ought to be balanced. Navigating this tension may be particularly difficult for care providers. In some instances, they are placed in the position of not being able to accommodate privacy requests of patients or family members because doing so could undermine ethical obligations of transparency and professional accountability. Health care authorities and professional bodies should provide guidance and support with respect to best practices for maintaining confidentiality that do not interfere with legal and ethical transparency requirements.

Our related findings showcase the tension between confidentiality and transparency and reveal how secrecy can enable stigma and vice versa. This tension can create both practical and ethical challenges that deserve further exploration. The second way in which our findings extend our understanding of stigma is that we learned that concerns about stigma can create other logistical challenges such as whether MAiD is mentioned on a death certificate or in an obituary, or whether family members feel comfortable accessing traditional grief supports. These findings add richness to our understanding of the stigma around MAiD in rural communities; not just that it exists, but how it can manifest.

3.

Working with limited resources

(a.) Rural communities have limited health care workers.

Of the available physicians and nurses in rural communities, there are even fewer who participate in the MAiD program. As noted earlier, we were told that there is a fairly high rate of conscientious objection to MAiD in the South Zone region. This means an even smaller pool of participating nurses and physicians. One physician mentioned that they became involved in the program specifically to help address this shortage.

> *"[I got involved because] I wanted the need to be filled, and especially in Southern Alberta where we have such a high number of conscientiously objecting practitioners."*
> *(Physician 1)*

This limited number of participating practitioners can have implications for patients in terms of the availability of MAiD information, assessment, and provision. This small pool of participating health care practitioners can also pose challenges for scheduling. Several participants mentioned that MAiD provisions can come with short notice and require participating nurses and physicians to go above and beyond their typical duties. A patient who has been approved may wait months before setting a date and then do so quite quickly if their condition deteriorates. This process requires participating health care workers to be flexible with their schedules to accommodate the patient's specific requests. This flexibility can be difficult since most nurses and physicians who are involved with MAiD are doing it casually or off the side of their desk. We were told that it can be difficult for them to adjust their work schedules to accommodate MAiD care or for them to find childcare on short notice to attend a provision.

Changes in MAiD legislation can further jeopardize the number of participating providers as some physicians and nurses may become concerned with the ethics of expanded eligibility. As the Federal Government considers expanding MAiD to include patients whose sole underlying condition is mental illness, health care providers may become apprehensive about their participation. We already saw this trend beginning as health care professionals who were participating in MAiD under Bill C-14, grew unsure whether they would participate in cases under Bill C-7 once the reasonably foreseeable death criterion was removed.

"Yeah. I'm nervous [about Bill C-7]... I'm scared. I don't know how I'm going to integrate this, because – I mean, I know I can't be forced to do anything, obviously, but I'm a little concerned how it's going to look if a person meets the criteria, but I'm not doing it... if they meet the criteria and yet I'm going 'well, I'm not comfortable with this one.'"
(Physician 7)

"Now with the new legislation, wow! It's just – it really made me think about whether I'm going to continue to do this. Because it's really very time consuming and I feel like [eligibility under C-7 is] very opinion based."
(Physician 2)

Such sentiments demonstrate that changes in legislation may further limit the pool of available providers. Health care professionals who previously participated in the MAiD program may now refrain or reduce the extent of their participation. This could further limit a patient's access to MAiD information, assessment, and provision, as well as place further strain on other health care workers providing MAiD.

Furthermore, these findings suggest that support for and opposition to MAiD exist not as fixed binary positions, but rather on a continuum. One's position on that continuum is dynamic and appears to be influenced by several factors including: 1) patient suffering; 2) personal and professional values and beliefs; 3) relationships with colleagues, patients and family, and community; and 4) changing MAiD policy and legislation.

Lastly, we were told that there is not much formal training available for rural providers looking to engage in this work. This may also contribute to the limited number of care providers willing and able to participate in MAiD.

"I will take referrals from my colleagues, but I will usually use the true rural teaching ideology of, you know, 'see one, do one, teach one' kind of thing. So, I'll do the first [MAiD provision] with them. But then my expectation is that for further cases, that they will work with the patient... That's kind of the mantra of like most rural residency programs, it's the 'see one, do one, teach one', right? So, the idea is that yeah, you get one crack at doing this in a supervised way. And then you do it independently. And then you start showing others."
(Physician 3)

"The education piece for MAiD [is a challenge] as well. I just did two shadows, and that was it for education. We've done one in-service via Zoom during COVID... but if you don't do it often, it's hard to remember how to do things."
(Nurse 5)

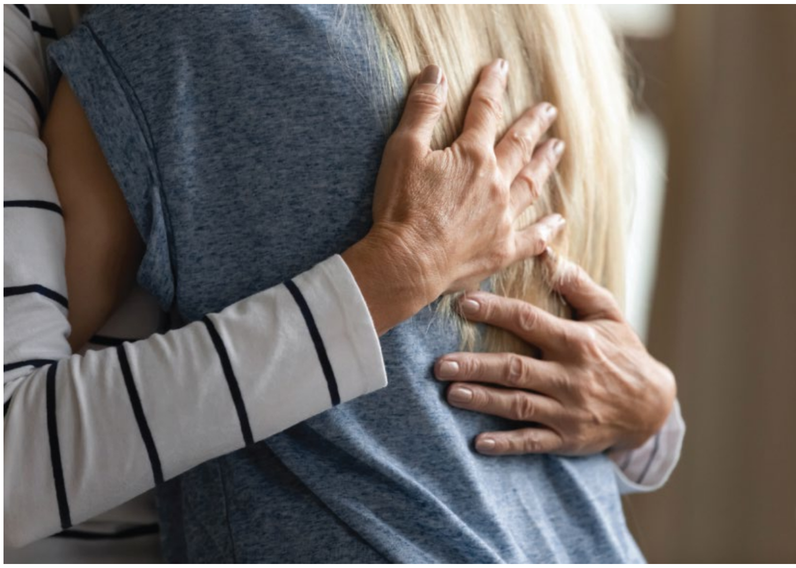
(b.) Access to specialized health and social services can be limited in rural settings.

Patients living in Southern Alberta may be at a greater distance from palliative care options, chronic pain support, specialist services, and other health and social services than those living in larger urban centres. Several of our participants spoke to this issue:

"So the Canada Health Act has a lovely clause that says that all Canadians have equal access to health care, etc. I kind of smile and nod; it's kind of – it sounds great, but if you slow that down it's hilarious because it's not even close to reality. It's just not true, right? If you live in [rural town] Alberta you can't possibly tell me that you have equal access to those who live across the street from the Foothills Medical Centre in Calgary... And then rural areas, the more remote areas it's true. Like, you don't have the same access [to palliative care], right? And so I think that has to be addressed in some way."
(Ethicist 2)

"And also, you know, disability supports, like accessing the resources for chronic pain in Southern Alberta is really limited compared to say in Calgary. So, there's also this urban/rural divide again."
(Physician 2)

One of the ways that some participants worked within and around limited access to health care services was to engage in interdisciplinary and intersectoral collaborations (e.g., with a local social worker or the centralized AHS MAiD Navigator) so that patients could be adequately informed of the full range of options that are available to them in their region. This was not the experience of all participants, nor does it address the lack of access to services that rural residents are promised under the Canada Health Act, but it was one way in which care providers worked with what was available to them.



(c.) Widely dispersed populations present travel-related challenges.

Southern Alberta's population is widely distributed across the region, which can mean a lot of driving for care providers, who typically travel to the patient for a MAiD provision. Supporting the patient to die in the place of their choosing (or at least, their current residence) is a valuable part of person-centred care, but the travel required to do this is not necessarily easy or efficient. We were told that although long drives are common and expected in rural areas, they can still be taxing, expensive, and, in poor weather conditions, perilous.

"Even arranging a fleet vehicle [can be a challenge]. My first experience was terrible. I had no signal lights, which I didn't know until I got to the location. And while that's not a MAiD-specific barrier or challenge, but it is actually, because we're in the role, we have to travel. So, I would like to get there safely."
(Nurse 5)

"There's probably some of us who would travel, if needed. People certainly have. It's not well supported that way, to have docs or nurses driving. It's not well funded. It would be probably on our own dime to do that kind of thing. And for an hour or two, you know, it's one thing. But further really remote areas are going to struggle with some of that."
(Physician 7)

Interestingly, we heard that pharmacists are key players that receive less attention in MAiD provision discourse (Ethicist 2; Physician 1; Physician 3; Nurse 5). When rural pharmacists object to participating in the practice, this makes the travel, logistical planning, and communication more complex for participating physicians:

> *"If it's an inpatient, if a person is at home, only one pharmacy in the whole South Zone in community will do them. So, in the east they're allowed to still get them from the hospital, but wherever you are in the west half of the zone, you have to get them from a single pharmacy in Lethbridge. Because it needs to have a sterile hood and there's only two pharmacies with sterile hoods and the other one is not supportive of MAiD, which is fine. But, it really restricts the availability and it takes a lot of time too for physicians. They made it now so a nurse can drive things out."*
> *(Physician 1)*

Several participants mentioned that the COVID-19 pandemic somewhat normalized the use of telehealth and video calling for the MAiD program in rural areas (Ethicist 1; Physician 1; Nurse 4). As a result, health providers relied increasingly on virtual communication to connect with specialists in other areas and efficiently facilitate the MAiD process for patients. However, they also noted some limitations of its use in the MAiD assessment process – and, of course, the necessity to be in person for the provision itself. That said, the increased use of video calling still offers an opportunity for greater communication between assessors and specialists who are spread out across a wide geographic region. In other words, it permits those involved with the program to provide effective care within the existing systemic and geographic constraints.

> *"So, if the provision takes place in the person's home, the physician has to physically pick up – like we have to prescribe everything, we have to travel to a pharmacy. So, for example, if somebody is in [rural town], if a physician there is going to do a provision, they have to drive into Lethbridge and then drive back with the medications, and then drive back into Lethbridge [to return the empty medications] and then drive back [home]."*
> *(Physician 2)*

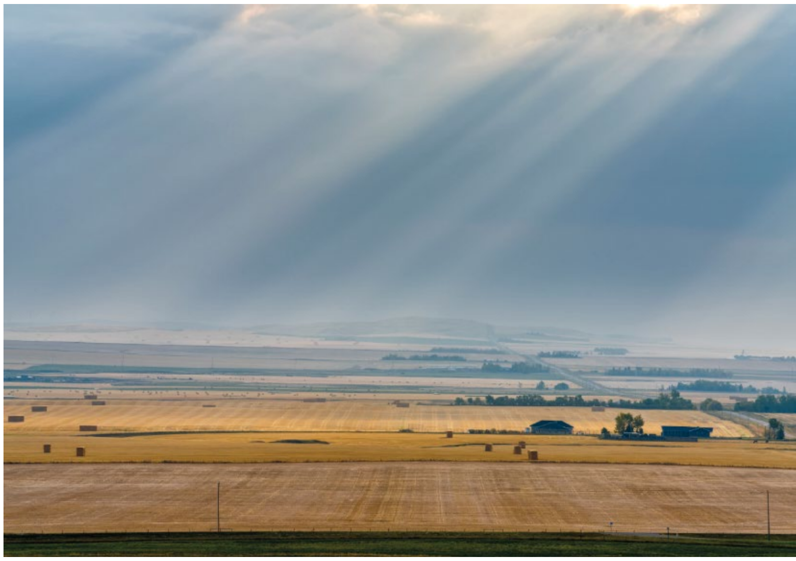
Finding #3 Implications & Considerations

Despite challenges associated with travel, staffing shortages, and limited resources in rural areas, our participants worked with the resources available to them and, generally, there was extensive praise for the individuals involved with the MAiD program and the high quality of care they provided to patients and their families. This does not mean that all participants' experiences were always positive, or that there was no acknowledgement of systemic problems with both MAiD and the health care system more broadly. Rather, our data reveal the extent to which care providers involved in MAiD in Southern Alberta went to great lengths to ensure positive patient and family experiences despite the imperfect systems within which they work.

Moving forward, there is a need to ensure that travel burden is minimized (and that related costs are not incurred by providers), that rural care providers receive adequate training and support for MAiD care, that scheduling for those involved with the program be flexible to accommodate this work, and that interprofessional and intersectoral collaborations, as well as video conferencing, be leveraged to support patients' needs.

Notably, none of our participants suggested that legally requiring conscientious objectors to participate in MAiD would be an ethical or effective solution to the staffing shortages that rural communities experience. In fact, several participants explicitly said otherwise. They said that this work should be something that one does because they believe in it, and they value respecting people's moral convictions. MAiD was described by many participants as a beautiful and profoundly human experience that should not be forced or overly clinical. Our participants noted that high quality care is possible when passionate people provide the service (i.e., people who are skilled in the right areas and bring a person-centred approach to the process). Given that we also heard that support for and participation in the MAiD program can be fluid, we recommend changing existing binary language about support/objection where it exists in related policies, reports, and guidelines so that discourses might become more inclusive and open to the various positions health care providers may hold at any given time.

To some extent, the concerns about limited health and social service provision in rural areas bore out in our empirical findings (Pesut & Thorne, 2019). Our participants confirmed that there is less access to palliative care, specialist services, chronic pain support, and social services. There are also concerns in the literature about MAiD potentially being seen as the only source of respite from suffering for isolated rural residents who cannot access these services (Collins & Leier, 2017). This concern was not evident in our data, but there is an important point to note; our data was collected leading up to and just following the passing of Bill C-7. As a result, our participants' experiences almost exclusively dealt with Track 1 cases (in which the patient had a reasonably foreseeable death). Track 2 cases (in which there is no reasonably foreseeable death) are more likely to reflect this concern – particularly as the legislation evolves to include those whose sole underlying medical condition is mental illness. Given Bill C-7's expanded eligibility criteria and the more limited access to health and social services in rural regions, issues related to the social determinants of rural health should remain under scrutiny going forward. Governments and health authorities have a responsibility to ensure that rural communities are not negatively impacted by the changes to MAiD legislation and that they are sufficiently resourced to prevent MAiD from becoming the perceived only source of respite for rural residents who are suffering.



Conclusion

Our findings confirmed, refined, and challenged ideas from the extant literature. Overall, our findings suggest that the particulars of the rural setting are significant for experiences related to MAiD care, that relational dynamics complicate decisions about involvement with the program, and that despite challenges associated with rural health service delivery, the individuals involved with the MAiD program in this region have worked with the resources available to them to provide quality care for patients and families.

Although the challenges of rural health care are quite well known, discussion of the benefits of rurality are largely missing from much of the literature. Our data shine a light on some of these benefits, which include dual roles, being known, and the rural landscape as a setting for a good death. In sum, place matters; rurality has distinct implications for MAiD. Going forward, both MAiD policy and service provision ought to be context-sensitive and attentive to these considerations.

References

Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying)*, 2nd Sess, 43rd Parl, 2021.

Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, 1st Sess, 42nd Parl, 2016 (assented to June 17, 2016), SC 2016, c 3.

Braun, V., Clarke, V. 2006. Using thematic analysis in psychology. Qualitative research in psychology, 3(2): 77–101. DOI: https://doi.org/10.1191/1478088706qp063oa

Braun, V., Clarke, V. 2022. Thematic analysis: A practical guide. Sage Publications.

Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331.

Chalmers, A. I., Joseph, A. E. 2006. Rural change and the production of otherness: The elderly in New Zealand. *Handbook of rural studies*, 388-400.

Collins, A., Leier, B. 2017. Can medical assistance in dying harm rural and remote palliative care in Canada? *Canadian Family Physician, 63*(3), 186-190.

Health Canada. (July 2022). Third annual report on Medical Assistance in Dying in Canada 2021. https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html#a3.2.

Herron, R., Skinner, M. 2018. Rural spaces and places of health and health care: handbook of health geography.

Kulig, J. C., A. Williams. 2012. Health in rural Canada. Vancouver, BC: UBC Press.

Mah, B. 2016, November 20. Rural Alberta faces more end-of-life care challenges: conference. Edmonton Journal. https://edmontonjournal.com/news/local-news/rural-alberta-faces-more-end-of-life-care-challenges-conference

Manduca-Barone, A., Brassolotto, J., & Waring, D. (2022). Medical assistance in dying in rural communities: A review of Canadian policies and guidelines. *Journal of Rural Studies*, 95, 223-231.

Pennings, R., and A. Reid. 2020. Canadians' views on assisted dying are complex. Policy Options. https://policyoptions.irpp.org/magazines/december-2020/canadians-views-on-assisted-dying-are-complex/

Pesut, B., Thorne, S., & Greig, M. (2019). Shades of gray: Conscientious objection in medical assistance in dying. *Nursing inquiry, 27*(1), e12308.

Pesut, B., & Thorne, S. (2019, September 26). *Why people choose medically assisted death revealed through conversations with nurses.* The Conversation. https://theconversation.com/why-people-choose-medically-assisted-death-revealed-through-conversations-with-nurses-122000?utm_source=dlvr.it&utm_medium=twitter.

Rainsford S., MacLeod R.D., Glasgow N.J., Wilson D.M., Phillips C.B., & Wiles R.B. (2018). Rural residents' perspectives on the rural 'good death': a scoping review. H*ealth & Social Care in the Community*, 26(3), 273-294. https://doi.org/10.1111/hsc.12385

Silvius, J. L., Memon, A., Arain, M. 2019. Medical assistance in dying: Alberta approach and policy analysis. *Canadian Journal on Aging, 38*(3), 397-406. https://doi.org/10.1017/S0714980819000175

Simpson, C., & McDonald, F. (2017). Rethinking rural health ethics. Springer International Publishing.

Smith, K. B., Humphreys, J. S., & Wilson, M. G. (2008). Addressing the health disadvantage of rural populations: How does epidemiological evidence inform rural health policies and research? *Australian Journal of Rural Health, 16*(2), 56-66. https://doi.org/10.1111/j.1440-1584.2008.00953.x

Truchon v. Attorney General of Canada, [2019] QCCS 3792.

Wilson, D. M., Fillion, L., Thomas, R., Justice, C., Bhardwaj, P. P., & Veillette, A. M. (2009). The "good" rural death: A report of an ethnographic study in Alberta, Canada. *Journal of palliative care, 25*(1), 21-29. https://doi.org/10.1177/082585970902500103

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