

Perceptions and Experiences of Medical Assistance in Dying Among Illicit Substance Users and People Living in Poverty

OMEGA—Journal of Death and Dying

0(0) 1–22


© The Author(s) 2019

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/0030222819889827

journals.sagepub.com/home/ome

Jessica Shaw¹ , Laura Harper²,
Emma Preston², Alysia Wright¹,
Michaela Kelly³, and Ellen Wiebe²

Abstract

Since medical assistance in dying (MAiD) became legal in Canada in 2016, there have been concerns about vulnerable people feeling pressured to end their lives. It is important to understand what people in marginalized communities know and feel about MAiD in order to help prevent any pressure to hasten death and to prevent any barriers to accessing assisted death. This qualitative study explored the perceptions and experiences of MAiD and other end-of-life care options with 46 people who were illicit substance users, living in poverty, or who worked with marginalized people in these communities. Six broad themes were identified: the importance of family, friends, and community; the effects of the opioid crisis; barriers to accessing end-of-life care services; support for MAiD; the difference between suicide and MAiD; and what constitutes a good death. Findings from this research may be used to help inform future legislation, professional guidelines, and standards of best practice.

¹University of Calgary, AB, Canada

²University of British Columbia, Vancouver, BC, Canada

³University of London, UK

Corresponding Author:

Jessica Shaw, Faculty of Social Work, University of Calgary, 2500 University Drive NW, Calgary, AB T2N 1N4, Canada.

Email: jcashaw@ucalgary.ca

Keywords

assisted dying, medical assistance in dying, end-of-life care, vulnerable populations, marginalization

On June 17, 2016, Canadians received the right to have an assisted death, if they were eligible according to the new medical assistance in dying (MAiD) law (Department of Justice, 2016). The law states that competent adults (over 18 years) who are suffering from a grievous and irremediable condition and whose natural deaths are within the foreseeable future are eligible. There have been concerns about vulnerable people being pressured into choosing an assisted death (Lerner & Caplan, 2015); however, demographic research from jurisdictions that have had assisted suicide (patient administered) or assisted death (doctor administered) for decades indicates that there is no evidence of this happening (Steck et al., 2014; Wineberg & Werth, 2003). On the contrary, research from jurisdictions where MAiD is legal suggests that people who choose an assisted death are most likely white, highly educated, urban, and wealthy.

Outside of a few articles that discuss the intersection of assisted dying and disability (Fadem et al., 2003; O'Brien, 2002; Riddle, 2017), there are few reports describing the perceptions and experiences of people from marginalized communities in relation to MAiD. Specifically, we did not find studies on the perceptions and experiences of people living in poverty. At the same time as exploring access to MAiD within marginalized communities, it is important to also explore access to other end-of-life care options, including palliative care and hospice care. MAiD has been legal in Canada since 2016, and initial research on the topic is just beginning to be published. Thus far, there has been no research on how marginalization influences a person's perceptions and experiences of MAiD in Canada.

With site locations in both Vancouver, BC and Calgary, AB, the objectives of this study were to explore the beliefs and experiences of people who are marginalized in relation to MAiD; to understand what questions, concerns, and desires they have about the availability of MAiD and other aspects of end-of-life care; and to continue to develop a research partnership network with community members as a basis for future collaboration.

It is important to understand what people in marginalized communities know about MAiD and what they perceive to be current issues related to it in order to both help prevent any pressure to hasten death and to prevent any barriers to accessing assisted death. This project contributes to the development of a new body of literature on MAiD in Canada. Furthermore, the Government of

Canada has explicitly stated that it intends to use research to inform amendments to current MAiD legislation (Department of Justice, 2016). Findings from this research may be used to help inform future legislation, professional guidelines, and standards of best practice.

Methods

The study was guided by the theoretical and methodological principles of Community-based Participatory Action Research which include that research be driven by and for the community in which it takes place; that research participants are valued as co-collaborators of knowledge; and that research is done to increase education and action on issues of social importance (Rubin & Babbie, 2008). Prior to beginning our research, during, and after the formal conclusion of our project, we developed and nurtured relationships with community organizations that serve people who are marginalized in Vancouver and Calgary. We met with the Calgary Allied Mobile Palliative Program (CAMPP), the Client Action Committee (CAC) of the Calgary Homeless Foundation, the Vancouver Native Health Clinic, the Vancouver Area Network of Drug Users (VANDU), PACE (an organization serving sex workers), and the Western Aboriginal Harm Reduction Society (WAHRS). We also received great support from The Alex Community Health Centre in Calgary and from a number of individual clinicians who preferred their workplace affiliations be kept confidential.

The need for this research emerged from the clinical work that we were doing with people who have experience with homelessness and illicit drugs. After the legalization of assisted dying in Canada, we started hearing increased rumblings of people, some of whom were our colleagues, who feared a *slippery slope* where the legalization of MAiD might lead to vulnerable people feeling pressured to end their lives or to being euthanized against their will. As clinicians and researchers who are committed to social justice, we desired to understand whether these fears were founded, and we turned to people in the communities where we worked to begin a conversation about how end-of-life care, including assisted dying, was being talked about and experienced. Beginning with the development of our research questions, throughout analysis, and onto knowledge mobilization, community members who were also research participants helped to guide this project. Participants who desired to be involved throughout the research process helped us to coordinate interviews, engage with community members, and direct research outcomes that extended beyond knowledge mobilization through scholarly publications. Some of these research outcomes are discussed in the Limitations and Next Steps section of this article.

Participants were recruited through social service agencies and professional networks of the research team. Research team members (J. S., L. H., E. P., and A. W.) conducted the interviews either in-person or over the telephone, based on

the preference and availability of the participant. A semistructured interview guide was developed by the team and included open-ended questions on the topic of MAiD, barriers and opportunities for accessing end-of-life care for vulnerable people, experiences with death and dying, pressure to end one's life, and religious beliefs that might affect one's opinion on end-of-life care and MAiD. Interviews ranged from 30 to 90 minutes and were collected over a period of 4 months.

Oral and written informed consent was obtained from each participant and a \$25 honorarium was provided to service users and peer community leaders. Interviews were conducted in English, audio-recorded with permission, and transcribed by the research team for analysis. One service user did not consent to audio recording, and the data from this interview were comprised of notes from the researcher. To ensure anonymity, participants were invited either to choose a pseudonym ($n = 16$) or to indicate that they would prefer to remain anonymous without a pseudonym ($n = 30$). Transcripts were coded with the interviewer's initials followed by a number, and in this article excerpts from the transcripts are quoted with either the chosen pseudonym or with the transcript code for participants who chose to remain anonymous.

The principal investigators (PIs) for this study were from two separate universities in western Canada; accordingly, ethics approval was obtained by both of the respective institutional research ethics boards. One of the PIs is a family physician, clinical professor, and MAiD provider; the other PI is a professor of social work. Our research team also included two medical residents, a doctoral student of social work, and a graduate student of public health. The interdisciplinarity of our team allowed us to develop and analyze this project as informed by both medical knowledge and social science theories. We conducted this research in both Vancouver, BC and Calgary, AB, which were the locations of the PIs, and where our professional connections aided our ability to contact and collaborate with local community organizations.

Sample

Through our community engagement work, we gathered data from a purposive sample of 47 individuals who were service users ($n = 28$), peer community leaders ($n = 12$), and formal service providers ($n = 7$). One service user decided to withdraw consent following their interview, so data from that individual are not included here (total participants for analysis, $n = 46$). Participants who were service users ($n = 28$) were actively involved with social agencies that provided harm reduction services, health and wellness programs, housing assistance, and other services for marginalized and vulnerable people. Community leaders were individuals who sat on board of directors and committees of these agencies and who were typically also service users ($n = 12$). Service providers included psychiatrists, physicians, nurses, social workers, and allied health professionals

($n = 7$). More than one third of participants ($n = 17$; 37%) identified as Indigenous; 16 participants (35%) identified as White, Canadian, or European; one participant (2%) identified as African Caribbean; and 12 participants (26%) did not disclose their ethnicity.

Analysis

Our work is emergent, meaning that this was one of the first studies to explore what people who are marginalized think and know about MAiD. We wanted to utilize an analytic approach that would limit the foregrounding of assumptive coding and honor the experience of our multidisciplinary research team. Therefore, rather than prescribing a rigid framework of preexisting codes for analysis, we chose to use an inductive analytic framework to guide the team in identifying emerging codes and categories as they were presented (Srivastava & Hopwood, 2009). One of the unique features of an inductive analysis framework is its adaptability in team-based research; as the researchers familiarize themselves with the data, they have the freedom to modify, add, or collapse codes (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Garrison, Cleveland-Innes, Koole, & Kappelman, 2006; Olesen, Droes, Hatton, Chico, & Schatzman, 1994; Turner, 1994). For the purpose of this study, we adapted the Framework Method developed by Gale et al. (2013) for working with multidisciplinary teams in health and social science research.

There were three steps to developing our inductive analytic coding framework: (a) initial comparative coding; (b) discussion and agreement on themes, codes, and code definitions; and (c) testing our framework on a sample of transcripts (Gale et al., 2013; Thomas, 2003). All of the transcripts were uploaded to Dedoose, a cloud-based qualitative analysis software program that could be accessed and edited by each member of the team in real time. Initial comparative coding was conducted on three transcripts by each of the researchers; each team member reviewed, highlighted, and coded meaningful segments of the text. Team members added the code and a brief description to the codes list in Dedoose. Next, the team met to discuss our preliminary findings and merged overlapping codes and eliminated or created new codes where needed (Smith & Firth, 2011). We tested the agreed-upon codes on another set of five transcripts. We met as a team once more to review the tested transcripts; at this stage, we found that we had reached coding saturation and came to agreement on the final codebook. The final codebook was organized by three categories: code, description, and an example from the text (Wen, Hudak, & Hwang, 2007); one of the team members completed coding the remaining transcripts.

Findings

Participants shared with us their stories about health, marginalization, and stigma. We found that the voices of service users, community leaders, and service

providers overlapped on these topics, demonstrating that there truly were more similarities than differences in the perceptions of MAiD and end-of-life care. We identified six broad themes in the data: (a) the importance of family, friends, and community; (b) the effects of the opioid crisis; (c) barriers to accessing end-of-life care services and supports; (d) support for MAiD; (e) the difference between suicide and MAiD; and (f) what constitutes a good death. In this section, we review each of these themes and include excerpts from the transcripts.

Importance of Family, Friends, and Community

Substance use, homelessness, and poverty are highly stigmatized and criminalized, and we were moved by the strong sense of community that many of our participants identified. Both biological family and street family were highly valued, and for people who were estranged from their biological families, the relationships that they developed with friends and community members were especially important. There was a sense of altruism and love that emerged from each of the participants' interviews, which showed up in participants' lives as dedication to community service, responsibility for their friends and family, and persistent hope that their lives and communities would improve.

Mostly it's just love. I just love these people, this neighborhood. It seems kind of morally incorrect for me to walk away from something. (Thursten)

But here, down here in the poorest part of the world, there was more community spirit, more community togetherness. When one guy's out, someone steps in and helps. (LH46)

What an amazing community. We step up. You know, the government or the city can't or won't do something. So we'll do what we can for other people, and I think it's pretty cool. (LH48)

We interviewed many of the service users at VANDU, which is a community agency that provides harm reduction services in the Downtown East Side (DTES) of Vancouver, BC. This allowed us to interact with participants in an environment that was familiar to them, where they felt comfortable, and at their own discretion. This form of *hanging out* resulted in some measure of rapport building and trust between the research team and the participants. It also meant that we were able to witness the love and community participants discussed in their interviews:

Yeah it's amazing. I mean to trust people that you know are criminally involved or they're doing drugs or whatever, and to be able to trust them with your life. They just give themselves when they have nothing. It's amazing. (Thursten)

This theme is closely linked to the effects of the opioid crisis that participants discussed.

Effects of the Opioid Crisis

When we interviewed participants at VANDU, they regularly spoke about the effects of the opioid crisis in the DTES and Canada. The lack of accessible medical services paired with the overprescription of opioids for pain has had devastating effects for services and people in the DTES:

To go from what was an accident, they hurt themselves, end up wired to opiates and now they have to risk their life every time. And then die. And it gets listed as an accident. It doesn't seem like really an accident. It seems like a lot of setting up for a very tragic and misguided end. (Thursten)

The people down here are being decimated. Literally, it's a genocide of the sneakiest behaviour possible. I believe that. (LH50)

The pervasive effects of the opioid crisis rippled through the stories that participants shared with us. Participants discussed being distrustful of the medical system, which many people perceived to be at best complicit in, and at worst responsible for the opioid crisis. In 2014, provincial regulatory bodies enacted policy changes that altered what drugs are offered to people who receive maintenance treatment for opioid addiction (Greer et al., 2016). The shift from Methadone to Methadose was problematic because the effects of Methadose wear off more quickly, meaning that people experienced withdrawal symptoms hours earlier than they experienced on Methadone. Trying to cope with feeling dope sick and an increase in unmanaged pain led some people whose symptoms were initially managed through Methadone maintenance treatment to return to using illicit drugs, which in turn led to an increase in unintentional overdoses (Greer et al., 2016). Some of our research participants felt that the change in treatment medication was a deliberate act by people who were trying to eradicate their community members.

Participants who tried to access medical services were also frustrated by the stigma that they dealt with when they did try to access care, including drug and alcohol treatment:

It's just so—like these are human beings, no matter what they do. They are still human beings and they have the right to the care and to get help when they need it, not to be tossed aside like garbage. (JS78)

But there ain't a person in this building that doesn't know someone that's been passed away and not a person that comes in here that doesn't know someone that's passed away. You could walk on the street, and everybody knows somebody.

Everybody knows somebody. And it's really taken an effect on the community. It's really taken a big effect. And especially how the health care is, like with the methadone/methadose, how they're just jerking everybody around. And it's like man, you're playing with somebody's life you know. Give them a chance. Just because they are a drug user? Give them a chance, man (LH46).

Participants who used drugs felt as if they were clumped together and stigmatized as a group, erasing the unique needs and identities of individuals. LH56 reminded us that "everybody who uses drugs is different," and that using drugs does not define a person.

Some participants identified that their friends and family use street and prescription drugs for pain management, occasionally resulting in death by overdose and other drug-related issues. This form of pain management was discussed particularly about people who were dealing with chronic pain and illness but did not have access to medical supports and services. For example, one participant told us that they preferred using heroin for managing their pain from Stage 3 cancer, as the chemotherapy treatments made them feel sick and increased pain (AW68). Another participant shared that "my pain medication is beer, and it's like, drink enough just to knock myself out so I can sleep . . . cause there's some days like I just, like I said I can't even walk a block anymore" (LH46).

Another effect of the opioid crisis is the prevalence of deaths. Participants talked about there being too much death in their community, particularly overdose-related deaths and terminal illnesses. These deaths have been both drug related and due to untreated terminal illnesses:

Now I hate walking down the street. I used to love walking down the street, but I hate it now because with a person dying every 6 hours, four people a day dying, it's very, very hard not to have somebody weekly that you know, and not just know by name, but know that is dying. And that's the bottom line. It goes up, but it never goes down. It's always at least four people a day. (LH56)

I've had a lot of friends that sadly are no longer with here, acquaintances. And it's kind of sad because whenever I hear the ambulance or whatnot, I'm always panicking as to who or if I'm going to know who has essentially not made it or whatever, you know. And I think we're a community in mourning and I think we're tired of mourning because you know—I don't go to memorials anymore because I've just gone to so many of them. I feel like just when I'm getting over one or a few of them, boom then there's another one. And it's like, my god, when is this going to stop. (Adrien)

It was clear from participants' stories that a significant issue for people experiencing marginalization are dealing with complex barriers to accessing services and supports for illness, end-of-life care, and illicit drug use.

Barriers to Accessing End-of-Life Care Support

Participants were asked to describe and explain their understanding of marginalization and then to discuss how they felt it influenced their ability to access end-of-life care supports. Whereas our conceptual understanding of marginalization was informed by an intersectional textbook definition, the lived experiences of our research participants provided a definitional depth that we now use to help explain what being marginalized can feel like. As Jane explained:

Marginalized means that you've been snowplowed to the edge of the road by the force of the prevailing society. And the prevailing society would be the snow plow and you would be the snow row on the edge of the road, that's marginalized. That means that if you're not willing to become part of the force and the energy of that society's focus, then you in fact are going to be pushed to the edge and you are going to be disregarded and you are going to be thought of as the garbage on the side of the road.

Other participants added to this conceptualization as they explained how being “marginalized, criminalized, and stigmatized” (LH47) were often experienced together. They spoke about numerous experiences where their racial identity, gender identity, Indigeneity, disability, and poverty intersected.

Some of the main barriers that prevented people from accessing quality end-of-life care included a lack of end-of-life care options and a lack of knowledge about what is available; stigma related to being homeless or to using illicit substances; and a lack of autonomy at the end of life. At the time of this writing, we were writing a more fulsome paper about findings related to the lack of autonomy and agency at the end of life for marginalized and vulnerable groups. In this section, we discuss barriers related to awareness of end-of-life care options and stigma associated with homelessness and substance use.

End-of-Life Care Options and Knowledge of Options Are Severely Lacking

The lack of awareness of end-of-life care supports meant that people with terminal illnesses faced barriers to accessing treatment and palliative care:

The last few months in the building I'm in, two or three people have died. And it's been four or five days before they've been found. And they were people who they knew were getting close to death, but they weren't lucky enough to be... in the hospice. (LH54)

Knowing where to go for information about MAiD was limited, though some participants said that they would feel comfortable talking to a local doctor about it. However, this instance actually breeds multiple complications,

not least of which being that many of the participants we spoke with utilized community health services and did not have a relationship with a specific family doctor. Adrien reflected on these challenges:

What about someone who would like to have an assisted death but can't find the doctor who supports them or the support services, and so ends up killing themselves in a suicide? I think that would be really sad and I think that that's where the government or the medical professions would have failed the person because I think that despite them not having those services there, I think if it's something that's going to become—and obviously by the sounds of it it's something that's going to become more—these services should definitely be in the tiniest communities too, just as much as they are in big cities like Vancouver.

When thinking about MAiD, another participant shared,

Yes. Yes. I don't think people realize—Is it legal? Can they do it? That's the thing. I don't think people actually know that. They know that if they say anything to a doctor, they are sent straight to psychiatric. (LH56)

This statement makes clear the power imbalances that exist between some patients and the medical professionals they interact with, where they will not tell a doctor what they need for fear that they will be ignored or committed.

One service provider stated, “You only have to look at research and journals to show that it's a severe lacking need, so I would be very surprised if marginalized people themselves were very aware of other opportunities” (AW60). Another participant reflected on what might keep them from having the type of death that they would want and they said, “Probably just the lack of knowledge... just like of knowledge I guess of the medical assistance or whatever” (AW70).

Stigma Related to Being Homeless and Substance Use

Participants who experience marginalization may also be stigmatized due to homelessness and substance use. This stigma is mostly encountered when participants would try to access medical and health services in their communities. One participant shared their frustration when they see their friends and community members refused treatment from medical centers:

And you're still refusing to help this person. Because of what? Your own—Why are you even in this job? That's not your decision. Here's a person, because she doesn't like the people, she's making her decision for him even though it's the wrong decision to make. The guy is dying of cancer and you're fucking—I just get kind of upset when I think about it. It's absolutely bullshit. I'm sick and tired of seeing

people down here who are in this condition being treated like this. It's a daily thing. It's a daily thing. (LH51)

Stigma created significant barriers to receiving help because it was not a matter of people not knowing where to go, or what resources were available to them. Rather, they were experiencing the negative effects of professional gatekeeping and facing systemic exclusion from the most basic human right to health and wellness. Adrien reflected that, "Down here it's a different world. The police and the society in general just treats this whole community just like we're third class, third world. It's very sad."

Although some participants shared that they were frustrated by the lack of services accessible to them, others took their reflections a step further and described the feeling of being eradicated through street-level genocide (LH50). In the DTES specifically:

The population isn't seen as poor, it's seen as drug users, even though there are just as many Chinese, old people, white people, black people, green, I don't care what color, that are in the poorest postal code living in these places. (LH56)

The purpose of this "cleansing" (LH54) seemed to be an effort to rid these communities of "the undesirables" so that the process of gentrification could continue:

Right now, it almost seems like there's a cleansing. An ethnic—not an ethnic cleansing, but a—what kind of cleansing would it call it down here? I mean it seems like everybody that's a drug user or heroin user is being annihilated. They are trying to force everybody out of this area. It's like they don't want to believe, or don't want to see what's going on. It's not very realistic. (LH54)

In the face of cleansings and eradication, some participants held fast to their love for their family in the community. Although participants were keenly aware of the stigma associated with them and the DTES, they did not take on this stigma for themselves. For some, that meant doing their part to keep the community safe:

It's because I feel responsible for my own use that I want to help—I want to keep [the neighborhood] clean and do my part. Most people think, "what do you mean you use? If you're picking up rigs aren't you against them?" No it's because I use. In fact, it's because I'm allowed to use that makes me functional in this position as a peer. (Thursten)

Support for MAiD

We found that most participants supported MAiD. The sense of love and community may contribute to participants' support of MAiD, in that participants

want their loved ones to be able to have a good death. Most of the participants supported MAiD for life-limiting conditions, especially in cases where a patient is in irremediable pain and discomfort. We identified three subthemes related to support for MAiD: (a) the distinction between physical and emotional illness, (b) no pressure to end their life due to marginalization, and (c) MAiD aligns with spiritual beliefs. One participant said that,

With MAiD, we're not preventing something. We're not preventing somebody from dying. They're dying anyways. It's just maybe giving them a sense of control and autonomy of what that looks like and when it happens and where it happens. (AW59)

Physical Illness Versus Emotional and Mental Illness

Whereas participants supported access to MAiD generally, most distinguished the difference between having a desire for an assisted death because of a physical illness—which was seen as acceptable—from having a desire for death because of a mental illness—which was seen as unacceptable. One service provider shared that,

I personally think it's long overdue and people should have the right to die. My only concern is just whether, you know, does that desire to, for end of life come from the pain and inability to manage it or just depression associated with being in palliative care. And I think that's a really sensitive, touchy area that we're not just giving people who may be depressed and suicidal a way out when they could potentially have the opportunity to live longer and fulfilling life. (Sebastian)

This excerpt brings forward concerns with what has caused the desire for someone to end their life. Another service provider said that,

From a psychiatrist perspective, I can't think of hardly any situation where the actual mental illness would be the result of the justifiable MAiD. (AW58)

One participant distinguished between patients who might have a chance to get better with treatment and those who are truly at the end of their life with no expectation of healing:

If somebody was just young and you know, what do you call them, there's a chance that they could go through chemo or something like that, I would say no. I don't think they should have an assisted death. Not until there's almost no choice left sort of. I wouldn't want to see somebody going through a lot of pain 'cause I've seen it. (LH55)

Service users, community leaders, and service providers all agreed that mental illness was both treatable and temporary. One service provider called for the use of a psychiatric evaluation as a part of determining eligibility for MAiD, while a participant shared that,

If you work hard and get help, you can still live a comfortable life even with depression and stuff like that. I don't think it should be a consideration for someone in that position to just say I don't want to live anymore, right? (AW73)

No Pressure to End Life Because of Marginalization

One participant, who was a registered nurse and worked full time with people on the street, wondered whether the idea of people living in poverty being pressured to end their lives was an idea that came from someone who had no experience with the homeless community. When asked whether she had heard anything about the concern of a slippery slope where the legalization of MAiD might mean people who are vulnerable or marginalized might feel pressured to end their lives, she said:

I have heard that, and I just kind of laugh. If somebody actually thinks that, they don't know this population. They haven't sat down and talked with a person in this population. The resiliency and the strength that you see in this population and the empathy for others that you see in this population far exceeds that of the greater—the general population—in the face of somebody going through things that most of us cannot imagine. So to make it this far and to have a sense of humor and to have, you know, just that—living day-by-day... they are always saying live in the moment. This population is able to do that probably better than anybody else. So, yeah. I think that they just haven't sat down and had a real conversation with anybody. (AW59)

Another participant who had personal experience with traumatic death expressed incredulity at the idea that someone who was wealthy and well supported by the health-care system might need help to end their own life. His belief was that people with strong social and medicolegal connections could access whatever resources they needed, and the idea that someone in such a privileged position might experience barriers in accessing end-of-life care did not fit with his understanding of how the health-care system works. Whereas death on the streets was so common, and suicide by intentional overdose possible, he mused that perhaps people who he felt ought to have easy access to medical resources could learn something from people who live on the street and figure out how to take care of things themselves.

Spirituality and MAiD

For people who identified as spiritual or religious, most felt that MAiD fit with their spiritual or religious beliefs. Thursten shared what he believed Creator would say about assisted death to someone who was dying:

It's your life. I gave you the life, I gave you the spirit. The body just comes with it. You're just a human, you can pretty much do whatever you want with your body. You're not going to punish your soul for, you know, a journey of fire because you chose to end your bodily life. Your bodily life didn't really matter to me. It was just a phase, but your spirit would always sort of exist.

Adrien thought that elders would respect an assisted death, saying that,

I find First Nations culture more than anything, we're very accepting and we're very accepting and very um just there to help people, my culture anyhow. It's open, it's for anyone. It's not just for people that are of a First Nations background you know. It's welcoming to all different walks of life and that most ceremonies I've been to are very open and the elders are very respectful and polite. They wouldn't be there to try and make you feel anything less than.

Observing an individual's customs, beliefs, and spirituality at the end of their life was considered integral to providing a good death. One service provider affirmed the importance of honoring the patient:

I think in literature we are always talking about having to make sure that things are culturally safe and culturally competent, but I think if you just treat everybody with that same dignity lens and person-centered care, you're going to capture all of that. And definitely asking them what is meaningful to them and do they have any spiritual beliefs that they want to incorporate into their care is a huge factor. You need to ask them or we can't know. (AW59)

Suicide Versus MAiD

For a more thorough explanation of how our research participants conceptualized the difference between suicide and MAiD, (see Wiebe, Shaw, Kelly, & Wright, 2019). A finding that we found to be especially interesting was that, even with the knowledge that MAiD is a legal and free option for Canadians, some participants disclosed that they would still prefer to be in control of their death through suicide. To clarify, all of these conversations were around hypothetical situations that were raised by the participant, where they were potentially nearing the end of life because of a life-limiting condition. As trained social workers and physicians, the interviewers assessed for risk of current suicidal ideation as necessary. Whereas some participants believed that each person

ought to have an absolute right to end their own life for any reason, others thought through some of the tensions that they felt when considering suicide for physical illness compared to suicide for emotional or mental illness.

I think if I was going to end my life, I would probably do it without medical help. But that's because I'm not suffering a terminal illness. My suffering is more emotional. I feel at the capacity to end my life on my own terms, but I could definitely relate to someone who might not have that such luxurious capacity to do that because I'm physically fit. I don't have any terminal illnesses, right, so my end of life at this point would be on my own terms, not on the illness' terms. I guess that's my biggest draw back with all this is that you're not going to be ending your life on your terms, you're going to be ending your life on your illness's terms and that's unfortunate. (AW71)

For participants who stated that even with the availability of MAiD they would prefer death by suicide, the most prevalent method of death would be through intentional overdose with drugs that they were familiar with and enjoyed. As one participant explained, an overdose would be a good death because “there would be no pain. I wouldn't feel anything and it's simple, [the drugs are] always around” (AW60). This idea was shared by others who said that with an overdose, “you just fall asleep and don't wake up,” (AW66) and that

if a person is so far into their addiction that the only way that they can find comfortability is going out that way, I think that shouldn't be a problem. There's a lot of people who would much rather see a person go in peace than they would, you know, struggling on a day-to-day basis, barrelled over and sick. (AW70)

A Good Death

Although the language of our research questions was focused on understanding needs and desires related to palliative care, including MAiD, we incorporated the essence of what we were looking for into the following interview question: What does a good death look like? For most people, a good death came after a person lived their life as long as possible, was painless and comfortable, peaceful, quick, and at a time and place where they could be surrounded by family (bio or street family) and friends. Whether the death was natural or assisted, there was a desire for calm and dignity at the end of life. Adrien shared that for him, a good death would include Indigenous community elders, who he believed would support him in either a natural or assisted death:

To have the cultural—not cultural, but the sacred medicines as we call them, there with me when I go. Someone is smudging and offering prayers for me you know,

and that there is an elder there to talk with me. You know, and I think most elders would be okay with that.

When we asked participants what a good death looked like, they often reflected quietly for a moment before answering. The responses were heartfelt, considerate, and stemmed from long histories of losing people. One participant said that death should be “clean, death should be beautiful, just the way life should be” (AW71). Jane reflected on her grandfather’s passing:

Calm. That was calm. And there was a lot of love. It was, it was calm. Yeah. Everybody knew what was going on, everyone acknowledged everyone else’s pain. There was no posturing. There was no room for that.

Vikki shared that when her aunt died, “We just didn’t want her to be in pain anymore so we kind of had to let her go, but it wasn’t easy.” These interactions with participants spoke to the universal desire for everyone to experience a good death, in whatever way that meant for them. In some cases, that might be an intentional overdose, or utilizing MAiD, or dying a natural death due to old age. Whatever the preference, the sentiments shared from participants were the same: Let us die with the peace, love, and dignity that we were not afforded in life.

Discussion

In this study, we have briefly introduced the main themes of our research, but we acknowledged that each theme could be and ought to be written about in a paper of its own. Two areas of discussion that we feel compelled to write about here are the differences in how the opioid crisis was discussed based on geographical location and the implications of there being both a lack of access to medical supports paired with a general support for MAiD and other end-of-life care options.

The Opioid Crisis: Vancouver Versus Calgary

As a research project that spanned across two site locations, we attuned ourselves to both the similarities and differences in our findings across locations. In general, there were no regional differences in the importance of friends, family, and community, in the barriers that were identified as problematic to accessing end-of-life care, and in participant support for MAiD. The main differences were how participants viewed the effects of the opioid crisis and in what participants wanted for next steps after the completion of the study.

In Vancouver, the experience of witnessing or knowing someone who had died because of opioid overdose was a major theme and was something that our participants wanted to draw our attention to. In Calgary, however, when the

opioid crisis was mentioned, conversations about it were often hesitant and the interviewers were reminded not to conflate homelessness with opioid addiction. There was a concern that focusing on deaths that were related to substance use would overshadow street deaths that occurred due to violence, exposure, or natural causes. Part of this discrepancy is likely due to the where the interviews took place. In Vancouver, researchers conducted most of the interviews out of VANDU, where most participants were actively involved in the DTES illicit drug scene. In Calgary, interviews were conducted near safer consumption sites (such as the one located at the Sheldon M. Chumir Health Centre), but most participants primarily identified as being a part of the community of people who had experience with homelessness, rather than with the substance using community. It therefore makes sense that there was a stronger focus on the effects of the opioid crisis with Vancouver participants.

In 2018 alone, more than 1,400 deaths in British Columbia were suspected to be caused by drug overdose (Bardwell, Fleming, Collins, Boyd, & McNeil, 2019; British Columbia Coroners Service, 2019; Kinshella, Gauthier, & Lysyshyn, 2018), and approximately 85% of the illicit drug overdose deaths were linked to the opioid fentanyl (British Columbia Coroners Service, 2019). The majority of deaths occurred in emergency shelters and low-rental or social housing, while zero deaths were reported to have occurred at safer consumption sites (Bardwell et al., 2019; British Columbia Coroners Service, 2019). Specifically in the DTES, the intense prevalence of opioid overdoses—especially those that lead to death—has overwhelmed the community, prompting numerous agencies to declare a state of emergency and to demand that more community-based research be done that will explore the benefits of harm reduction approaches, safer consumption sites, and explain some of the links between the Vancouver housing crisis and opioid use (Bardwell et al., 2019; Boyd, Fast, Hobbins, McNeil, & Small, 2017; Boyd, Murray, SNAP, & MacPherson, 2017; British Columbia Coroners Service, 2019; Cheng et al., 2018; Kerr, Mitra, Kennedy, & McNeil, 2017; Kinshella et al., 2018; Scheuermeyer et al., 2019; Young & Fairbairn, 2018). Although we did not intend for our research to focus on the opioid epidemic, we acknowledge that any research that is done about death and dying in the DTES must include an awareness and sensitivity to the prevalence of overdose-related deaths in the community.

Balancing the Need to Protect With the Right to Access

The Vulnerable Persons Standard (VPS-NPV, 2017) is a document and set of guidelines that was developed by a team of scholars who have expertise in medicine, ethics, law, and vulnerability and was created in response to the legalization of MAiD in Canada. It outlines five evidence-based safeguards that ought to be considered when assessing a person who may be vulnerable to coercion in their request for MAiD. In its consideration of the social

determinants of health and of psychosocial factors such as loneliness and stigma, the Standard offers that:

People who request a physician-assisted death can be motivated by a range of factors unrelated to their medical condition or prognosis. These factors make some people vulnerable to request an assisted death when what they want and deserve is better treatment—to have their needs for care, respect and palliative and other supports better met. (VPS-NPV, 2017, para. 7)

We agree with the Standard that circumstances that are unrelated to a person's medical diagnosis should not be a driving factor in their request for MAiD, and we recognize the importance of strong publicly funded health care, and adequate and accessible social services. In the public narratives about vulnerability in relation to assisted dying, we wonder if perhaps it is easier to deny MAiD because of concerns about people who are marginalized lacking the capacity to consent, than it is to accept the social responsibility for the fact that people do not have meaningful social relationships, medicolegal connections, or access to adequate resources.

We would offer that clinicians, policymakers, activists within marginalized communities, and MAiD scholars ought to be aware of the socioeconomic factors that influence a person's health-care decision-making, while also seeking to ensure that individuals are not denied access to MAiD because of their perceived vulnerability. As problematic as it would be if a person were pressured to end their life because of their socioeconomic circumstances, so too would it be unethical to deny a person their right to an assisted death because of their socioeconomic circumstances. In the second senate reading of the bill that legalized MAiD in Canada, Senator Petitclerc stated that, "there is a fine line between protecting the vulnerable and patronizing them" (Petitclerc, 2016, para. 24). Having worked with people who have sought MAiD since its legalization, we know that there is not a person who presents for MAiD who is not vulnerable. Having a life-limiting diagnosis immediately defines a person as being in a vulnerable state, and assessing for additional factors of vulnerability is something that ought to be done for all people who present for medical treatment—whether it be related to end-of-life care or their health more generally.

Next Steps

Although we reached theme saturation with our participants who experienced homelessness and were illicit substance users, we did not explore the perceptions and experiences of people who were vulnerable in other ways, such as those who were cognitively or physically disabled. We also acknowledge that most of our participants were not living with a life-limiting diagnosis when we spoke with them, and that research needs to be done on what people who are marginalized

and are actively dying think about assisted death. Future research should also address best practices for knowledge dissemination and ways of decreasing stigma in the health-care system. In addition, there are a number of other cultural groups whose experiences were not captured in these interviews and whose experiences of end-of-life care should be explored. More research is needed to investigate Indigenous ways of knowing at the end of life using participatory, decolonizing methodologies.

As a research project that was rooted in the principles of community-based participatory action research, our accountability to the communities with which we worked was as important to us as our accountability to share knowledge with research communities. At the request of research participants, initial findings from this research project were shared in a town hall meeting at VANDU in Vancouver and were used to create a proposal for the establishment of a permanent memorial site that recognizes people who have died while experiencing homelessness in Calgary. We continue to work with people in Vancouver and Calgary to further fulfill our ongoing ethical commitments to engage in knowledge mobilization activities that are driven by and for the people who so generously shared their thoughts and experiences for this project.

Finally, we acknowledge that the requirement to crop rich narratives into short highlights for the purposes of a manuscript inevitably leads to a loss of depth that simply cannot be translated into quotes or summaries. This study is one of several that have emerged from our research, and we will continue to work with the stories of our research participants to ensure that their experiences are shared in different ways and for different audiences. At the time of this writing, we were in the process of either writing or publishing papers from this research project that will more thoroughly delve into some of the themes identified here.

Conclusions

Among people who are street involved, there is a severe lack of knowledge of end-of-life care options, and where there are palliative care services for people who are street involved, they are limited and underresourced. Participants in the Vancouver DTES described the large impact of the opioid crisis on experiences of death where “accidental deaths” outnumber “progressive or slow deaths.” This trauma strengthened their desire to support their peers and their desire for a good death. Participants across both site locations (Calgary and Vancouver) had a low level of knowledge about end-of-life options such as palliative care, hospice, and MAiD. They identified stigma and lack of autonomy as barriers to accessing end-of-life supports. They talked about the importance of family, friends, and their community at the end of life. Most of the participants supported MAiD, but only when limited to those suffering at the end of life. Most did not feel that marginalization resulted in pressure to consider or

accept MAiD. On the contrary, there were concerns that MAiD would be inaccessible to people who qualified for it because of a life-limiting diagnosis. At least for people who are vulnerable because of a lack of housing or because of substance use, this finding contradicts the social idea of there being a slippery slope where vulnerable people are being coerced or pressured to end their lives. These findings have policy and practice implications for how end-of-life care services are funded and offered in communities across Canada.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research project was funded through a University of Calgary SSHRC Explore Faculty Seed Grant.

ORCID iD

Jessica Shaw  <https://orcid.org/0000-0002-2331-2440>

References

- Bardwell, G., Fleming, T., Collins, A. B., Boyd, J., & McNeil, R. (2019). Addressing intersecting housing and overdose crises in Vancouver, Canada: Opportunities and challenges from a tenant-led overdose response intervention in single room occupancy hotels. *Journal of Urban Health, 96*, 12–20.
- Boyd, J., Fast, D., Hobbins, M., McNeil, R., & Small, W. (2017). Social-structural factors influencing periods of injection cessation among marginalized youth who inject drugs in Vancouver, Canada: An ethno-epidemiological study. *Harm Reduction Journal, 14*(31), 1–11.
- Boyd, S., Murray, D., SNAP, & MacPherson, D. (2017). Telling our stories: Heroin-assisted treatment and SNAP activism in the Downtown Eastside of Vancouver. *Harm Reduction Journal, 14*(27), 1–14.
- British Columbia Coroners Service. (2019, February 7). *Illicit drug overdose deaths in BC*. Retrieved from the Government of British Columbia Coroners Service website: <https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/coroners-service/statistical/illicit-drug.pdf>
- Cheng, T., Small, W., Dong, H., Nosova, E., Hayashi, K., & DeBeck, K. (2018). An age-based analysis of nonmedical prescription opioid use among people who use illegal drugs in Vancouver, Canada. *Substance Abuse Treatment, Prevention, and Policy, 13*(41), 1–11.
- Department of Justice. (2016). *Legislative background: Medical assistance in dying (Bill C-14)*. Ottawa, ON: Government of Canada. Retrieved from <http://justice.gc.ca/eng/cj-jp/ad-am/index.html>

- Fadem, P., Minkler, M., Perry, M., Blum, K., Moore, L. F., Rogers, J., & Williams, L. (2003). Attitudes of people with disabilities toward physician-assisted suicide legislation: Broadening the dialogue. *Journal of Health Politics, Policy and Law*, 28(6), 977–1001.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117.
- Garrison, D. R., Cleveland-Innes, M., Koole, M., & Kappelman, J. (2006). Revisiting methodological issues in transcript analysis: Negotiated coding and reliability. *The Internet and Higher Education*, 9(1), 1–8.
- Greer, A. M., Hu, S., Amlani, A., Moreheart, S., Sampson, O., & Buxton, J. A. (2016). Patient perspectives of methadone formulation change in British Columbia, Canada: Outcomes of a provincial survey. *Substance Abuse Treatment, and Policy*, 11, 3.
- Kerr, T., Mitra, S., Kennedy, M. C., & McNeil, R. (2017). Supervised injection facilities in Canada: Past, present, and future. *Harm Reduction Journal*, 14(28), 1–9.
- Kinshella, M.-L. W., Gauthier, T., & Lysyshyn, M. (2018). Rigidity, dyskinesia and other atypical overdose presentations observed at a supervised injection site, Vancouver, Canada. *Harm Reduction Journal*, 15(64), 1–7.
- Lerner, B. H., & Caplan, A. L. (2015). Euthanasia in Belgium and the Netherlands: On a slippery slope? *JAMA Internal Medicine*, 175(10), 1640–1641.
- O'Brien, N. (2002). Prospective legal immunity: A disability rights perspective on assisted dying. *Kings Law Journal*, 23(2), 149–161.
- Olesen, V., Droes, N., Hatton, D., Chico, N., & Schatzman, L. (1994). Analyzing together: Recollections of a team approach. In A., Bryman & R.G., Burgess (Eds.), *Analyzing qualitative data* (pp. 111–128). London, England: Routledge.
- Petitclerc, C. (2016). *Criminal code bill to amend—Second reading: The honourable Senator Chantal Petitclerc*. Retrieved from <https://sencanada.ca/en/speeches/sen-petit-clerc-bill-c-14-second-reading/>
- Riddle, C. A. (2017). Assisted dying and disability. *Bioethics*, 31(6), 484–489.
- Rubin, A., & Babbie, E. R. (2008). *Research methods for social work* (6th ed.). Belmont, CA: Thomson.
- Scheuermeyer, F. X., Grafstein, E., Buxton, J., Ahamad, K., Lysyshyn, M., DeVlaming, S., ... Gustafson, R. (2019). Safety of a modified community trailer to manage patients with presumed fentanyl overdose. *Journal of Urban Health*, 96, 21–26.
- Smith, J., & Firth, J. (2011). Qualitative data analysis: The framework approach. *Nurse Researcher*, 18(2), 52–62.
- Srivastava, P., & Hopwood, N. (2009). A practical iterative framework for qualitative data analysis. *International Journal of Qualitative Methods*, 8(1), 76–84.
- Steck, N., Junker, C., Maessen, M., Reisch, T., Zwahlen, M., & Egger, M. (2014). Suicide assisted by right-to-die associations: A population based cohort study. *International Journal of Epidemiology*, 43(2), 614–622.
- Thomas, D. R. (2003). *Qualitative data analysis: Using a general inductive approach*. Auckland, New Zealand: University of Auckland, School of Population Health. Retrieved from <http://www.frankumstein.com>
- Turner, B. A. (1994). Patterns of crisis behaviour: A qualitative inquiry. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data* (pp. 194–215). London, England: Routledge.

- VPS-NPV. (2017). *The vulnerable persons standard*. Toronto, ON: Author. Retrieved from <https://vpsnpv.squarespace.com/>
- Wen, C. K., Hudak, P. L., & Hwang, S. W. (2007). Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *Journal of General Internal Medicine, 22*(7), 1011–1017.
- Wiebe, E., Shaw, J., Kelly, M., Wright, A. (2019). Suicide vs Medical Assistance in Dying (MAiD): a secondary analysis of three qualitative studies. *Death Studies*. doi:10.1080/07481187.2019.1614110
- Wineberg, H., & Werth, J. L. (2003). Physician-assisted suicide in Oregon: What are the key factors? *Death Studies, 27*(6), 501–518.
- Young, S., & Fairbairn, N. (2018). Expanding supervised injection facilities across Canada: Lessons from the Vancouver experience. *Canadian Journal of Public Health, 109*, 227–230.

Author Biographies

Jessica Shaw, PhD, RSW, is a professor of social work at the University of Calgary. Her program of research focuses on marginalized experiences of moralized healthcare, including assisted dying and abortion.

Laura Harper, MD, CCFP, is a family physician who lives and practices in Vancouver, BC.

Emma Preston, PhD, MD, CCFP is a family physician with the Kílala Lelum Urban Indigenous Health and Healing Cooperative in Vancouver, BC.

Alysia Wright, has worked in the community development sector since graduating from the University of Montana in 2011. She is currently completing her PhD with the Faculty of Social Work at the University of Calgary, where her research focuses on understanding experiences of social inclusion and wellness among oil workers in Alberta.

Michaela Kelly, BSc, graduated from Quest University where she focused on public health and gender studies. She is currently completing her MSc in Epidemiology through the University of London and works as a research assistant on projects related to assisted death and women's health.

Ellen Wiebe, MD, CCFP, FCFP, is a clinical professor in the Department of Family Practice at the University of British Columbia and is the medical director of Willow Clinic in Vancouver, BC. After 30 years of full-service family practice, she now restricts her practice to women's health and assisted death, as a provider, as an advisor for other healthcare professionals, and as a widely published researcher.