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Narrative Inquiry in Bioethics, Ahead of Print, (Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/nib.0.a956587*

RESEARCH ARTICLE

Dignity Narratives in Complex MAiD Bereavement Stories: A Critical Qualitative Analysis

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Conflicts of Interest. The authors declare no conflicts of interest with this work.

Abstract. A death by medical assistance in dying (MAiD) is often equated with a good death or a death with dignity, yet how MAiD-bereaved family members in Canada conceptualize the relationship between dignity and MAiD is currently unknown. Using a critical narrative inquiry approach, this article explores how family members with complex MAiD experiences constructed the concept of dignity in their bereavement stories. Dignity is conceived of as a thick, culturally relative concept with descriptive and evaluative meanings. Twelve family members from three of Canada's provinces (Alberta, British Columbia, and Ontario) completed narrative interviews about their experiences with complex MAiD bereavement.

The interview transcripts are presented as short stories that portray how participants talk about dignity in relation to MAiD. These stories were analyzed from a critical narrative analysis approach that examined how institutional discourses are weaved into everyday stories about personal experience. The analysis identified three dignity narratives in participants' stories: the Dignified MAiD Narrative, the Traumatic MAiD Narrative, and the Unjust MAiD Narrative. The Dignified MAiD Narrative may provide solace to family members who agreed with their loved one's decision to choose MAiD; however, this narrative may simultaneously create moral tensions by setting unrealistic expectations for family members. The Traumatic and Unjust MAiD Narratives provide counter perspectives that challenge the notion that MAiD unequivocally leaves a legacy of a dignified, good death.

Keywords. MAiD, Bereavement, Dignity, Critical Narrative Analysis, Narrative Inquiry

Introduction

Euthanasia is etymologically derived from the Greek *eu* (good) and *thanatos* (death), and proponents often use the term synonymously with "death with dignity" and "the right to die" (Messinger, 1993). In Canada, the term medical assistance in dying (MAiD) refers to the legislated process whereby a physician or

nurse practitioner can provide eligible patients with medication to end their lives. The eligibility includes being at least 18 years old, mentally competent, having a medical condition that is grievous and irremediable, making a voluntary request, and giving consent (Government of Canada, 2024). Patients must submit a witnessed written request and have two independent medical assessments. If it is determined that the patient's natural death is not reasonably foreseeable, there are additional safeguards that must be satisfied. These include being informed of available means to alleviate suffering, such as palliative care services, and a 90-day waiting period (Government of Canada, 2024). This legislation is based on Bills C-7 and C-14 passed in 2016 and 2021, respectively. The legislation was supported by advocacy organizations such as Dying with Dignity Canada, Association Québécoise pour le droit de mourir dans la dignité, and the Canadian Civil Liberties Association. Each of these organizations claims to defend Canadians' rights, dignity, and freedom to choose an assisted death.

The concept of dignity carries complicated and contested definitions across time, space, and disciplines (Debes, 2023). Modern definitions of the term often reference the United Nations' 1948 Declaration of Human Rights, the first article of which reads, "All human beings are born free and equal in dignity and rights." The preamble to the Declaration describes a relationship between the inherent dignity and worth of persons with fundamental, inalienable human rights that form the foundations of equality, peace, freedom, and justice. Despite the primacy of the relationship between dignity and rights in the Declaration, a dearth of shared understanding about what dignity is or how it ought to inform juridical decision-making on human rights issues persists (McCrudden, 2008). McCrudden (2008) defines the basic minimum content of human dignity as follows: "each human being possesses an intrinsic worth that should be respected, that some forms of conduct are inconsistent with respect for this intrinsic worth, and that the state exists for the individual not vice versa" (p. 723). Various definitions and interpretations of dignity may be constructed differently based on political, ethical, religious, or legal grounds.

For example, there are several theories of dignity within the field of bioethics alone (Ashcroft, 2005). These include cognitivist and metaphysical theorists who sought to discover universal moral features embodied by all humans (Kass, 2002). There are those who have argued that the concept of dignity is inherently based on autonomy (Beyleveld & Brownsword, 2001), or that dignity ought to be considered in relation to social capabilities and functioning (Nussbaum, 2000; Sen, 1992). Finally, Ashcroft (2005) suggested there are bioethicists who view theorizing about dignity to be an unnecessary and incoherent project altogether (Macklin, 2003).

How individuals speak about dignity colloquially may differ from how it is defined by philosophers, political actors, or legal scholars. The purpose of this article was not to develop a new theory of dignity, nor test out competing theories from various disciplines. Instead, we conceived of dignity as a thick, culturally relative concept with descriptive and evaluative meanings, following Ashcroft's (2005) suggestion to "explore what 'dignity' cultures are like, and the practices of talk and action that take dignity as their object" (p. 680). In the following sections, we explore how the concept of dignity is constructed through language in relation to death, dying, MAiD, and bereavement.

Good/Bad Death, Dignity & MAiD

The relationship between dignity, self-determination, and good death is promoted by right to die organizations internationally. Many of these organizations promote the narrative that an assisted death is a dignified death. They advocate for autonomy, choice, and control and they support grassroots and legislative initiatives to legalize and legislate assisted dying. As Dying With Dignity Canada (2025) states on their website, "Everyone can choose their good death." This section examines empirical and theoretical scholarship on the relationship between good/bad death, dignity, and MAiD.

The contemporary concept of good death is influenced by the western hospice movement. Both hospice and palliative care practices focus

on improving the quality of life for patients and their families while decreasing pain and suffering (Hughes et al., 2008; World Health Organization, 2020). Palliative care nurses have described good death as occurring when patients die peacefully without pain and suffering, can prepare for death, and are surrounded by loved ones (De Jong & Clarke, 2009). A systematic review investigating definitions of good death found that good death often includes respecting the patient's preferences for care and treatment, dying without pain, supporting the emotional well-being of patients, the support of family, dignity, feeling a sense of life completion, having spiritual or religious comfort, maintaining good quality of life and relationships with health care providers (Meier et al., 2016).

Bad death, on the other hand, is identified by factors such as physical pain and suffering, sudden or unexpected death, a prolonged dying process, and disrespect or lack of dignity displayed toward the dying person (Wilson & Hewitt, 2018). Bad deaths can occur when individuals have no control over their circumstances, are not able to die in the place of their choosing (such as at home), when low quality of life is mechanically prolonged, when there is immense pain and suffering (including physical, spiritual, and existential), and when individuals are uncomfortable, angry, or agitated at the end of life (Wilson & Hewitt, 2018).

A Dutch media analysis found depictions of assisted dying to be the primary representation of good death in old age (van Wijngaarden & Sanders, 2022). Dutch newspapers leveraged the concept of dignity in two distinct interpretive repertoires, the choice-repertoire and the care-repertoire (van Wijngaarden & Sanders, 2022). In the most common representation, dignity was constructed as being important for choice, control, and the enactment of autonomy at the end of life. In response to this dominant representation, the care-repertoire presented care and social connection as central tenets required for a dignified death. Divergent conceptions of dignity can thus be employed in myriad ways to support a variety of positions on what characterizes a good death.

A scoping review of patient definitions of dignity at the end of life found the concept to be characterized by respect for individual personhood, self-determination, preserving familial relationships, and providing care and support (Chua et al., 2022). Similarly, Meier and colleagues (2016) describe dignity as "being respected as an individual and maintaining independence" (p. 5). Maintaining patients' dignity at the end of life may help to facilitate a peaceful death experience and avoid bad death (Hayden & Dunne, 2022).

The narrative that MAiD provides a dignified good death is disseminated through legal and medical knowledge, legislation, and enacted by medical professionals within publicly funded institutions. A textual example of what the enactment of this narrative looks like can be found in Green's (2022) book *This is assisted dying: A doctor's story of empowering patients at the end of life.* Green's portrayal of dignity is reflective of the narrative that is promoted by the assisted dying advocacy organizations mentioned above. Green writes, "I hoped the hospital staff would view MAiD as I did, as patient-centred care that tried to restore some control and dignity when a person could no longer tolerate living" (p. 73).

An opposing view of the relationship between dignity and assisted dying posits that intentional killing of the self or another does not support dignity; rather, it violates human dignity (Muders, 2017). Kaczor and George (2017) argue that death with dignity is a dangerous euphemism, "masking the reality of what is at issue in these cases, which is not precisely death or dying but, rather, intentional killing. Such euphemisms obscure the reality that all human persons are equal in fundamental dignity and that this basic value remains undiminished even at the end of life, even in the midst of suffering" (p. 82). From this perspective, all humans have equal dignity and equal value that is not lessened by experiences of illness, pain, or suffering. Similarly, in exploring the relationship between dignity-based requests for MAiD and physical disability, Wasserman (2017) argued that physical disability should not be itself an indignity. Rather, the indignity is a product of the social stigma that society carries toward people living with physical disabilities. Wasserman's position questioned the legitimacy of the argument that physical disability leads to

a loss of dignity and, likewise, that dignity can be reclaimed through MAiD.

These varying theories and perspectives construct part of the narrative landscape within which family members develop their own views about the relationship between dignity and MAiD. The described theories and public discourse about MAiD may influence family members' perspectives and experiences. The following section provides an overview of research on family members' experiences with MAiD in Canada.

Family Perspectives on Dignity and MAiD

In Canada, healthcare professionals encourage patients to involve their family members in MAiD decision-making and in preparing for and participating in the MAiD procedure (Beuthin et al., 2022; Frolic et al., 2024; Hales et al., 2019; Holmes et al., 2018; Oczkowski et al., 2021; Thangarasa et al., 2022). Beuthin and colleagues (2022) found that participating in MAiD can be a peaceful experience for family members, and the procedure may be an opportunity for ceremony and meaning making; others, however, have found the experience to be "rooted in complexity, ambiguity, and ambivalence" (Frolic et al., 2024, p. 1). Canadian family members have reported unexpected experiences of social judgement, secrecy, guilt, and trauma (Crumley et al., 2023) and challenges, including logistical issues, family discordance, and internal conflict (Serota et al., 2024). While witnessing MAiD can be a peaceful event for some family members (Beuthin et al., 2022; Holmes et al., 2018), it can be traumatizing for others (Crumley et al., 2023; Serota et al., 2023). Some individuals choose not to involve their families, and some do not disclose their decisions to their families (Ho et al., 2021). Given the legislation around health information privacy and healthcare professionals' duty of confidentiality, it is up to the individual seeking MAiD to decide the extent to which they would like family members to be involved.

Oczkowski and colleagues (2021) are the only scholars, to our knowledge, who have explored the concept of dignity in relation to family members' MAiD bereavement in Canada. Their qualitative study identified improvement opportunities for patients who had requested MAiD and their family caregivers. They found that MAiD provides an avenue for control which can foster dignity and independence, and clinicians should "provide compassionate care aimed at maintaining an individual's dignity—what this means will vary between patients and families" (p. 7). The authors identified aspects of care that may be involved in dignity, such as control, independence, and compassion. Oczkowski and colleages (2021) do not provide an in-depth discussion about how family caregivers employ the concept while storying their experiences. The current research aims to address this gap.

How concepts of dignity influence family members' experiences of involvement in MAiD decision-making and MAiD bereavement is currently unknown. Understanding how family members draw upon dignity narratives in their stories about MAiD bereavement can help us explore how family members conceptualize dignity in relation to their loved one's choice to have MAiD. By mapping the diverse ways family members talk about dignity, we can draw connections to the knowledge regimes, such as law and medicine, that may impact social conceptions of MAiD.

Methods

Design

This research study was designed to collect diverse stories about the MAiD bereavement experience and the challenges encountered by family members. We conducted narrative interviews (Janesick, 2010; Kim, 2016) with family members who had complex bereavement experiences marked by discordant views, disagreement, family conflict, or differences in understanding about MAiD. This research used a critical narrative analytic approach to story and analyze the dignity narratives that family members with complex MAiD bereavement draw upon in their stories about MAiD (McCormack, 2000a, 2000b, 2004; Souto-Manning, 2012, 2014). The purpose of this article is not to suggest that there is a correct or incorrect way to speak about dignity and MAiD; rather, we seek to understand this diverse landscape of interpretations.

Participants

Information about the research study was disseminated through a variety of channels, including Canada Virtual Hospice, Bridge C-14, the Canadian Association of MAiD Assessors and Providers, on Facebook and Twitter, and by two therapists who contacted us asking if they could share the information with their clients. We were contacted by 21 individuals interested in participating in the study; 15 were eligible after screening, and 12 chose to complete a narrative interview. To participate in the study, individuals needed to be at least 18 years old, fluent in English, and residents of Canada. They also had to be family members or close friends of someone who had died by MAiD and have experienced disagreement, family conflict, or differing understandings related to MAiD. Since the interviews focused on bereavement, at least four months had to have passed since the MAiD occurred. Finally, individuals who were currently receiving mental health counselling to manage the grief associated with this loss were not eligible to participate so as not to interfere with their treatment.

Five participants chose to be interviewed over the phone, and seven chose to be interviewed on Zoom. The interviews lasted between 41–94 minutes. Each interview began with a short demographic survey. When asked about their relationship to the person who had chosen MAiD, participants shared that their mothers, fathers, husbands, sisters, brothers, and close friends chose MAiD. There was a large range of time since the MAiD occurred, from 4–6 months to greater than 36 months, with the MAiD deaths occurring in Alberta, British Columbia, and Ontario. All of the participants described themselves as white, of European descent, and eight identified as women, three as men, and one as nonbinary.

Participants represented a variety of age categories, with one-quarter (3) being between 45–54 and one-third (4) between 65–74. Finally, all participants had completed high school, and seven had earned a master's, professional, or doctoral degree. Participants self-selected to participate in this study, and their demographic qualities may not be representative of families impacted by MAiD across the country. It is, however, noteworthy that preliminary demographic research suggested individuals seeking MAiD were likely to be from a higher income quintile (Downar et al., 2020).

Data collection

Participant recruitment took place from December 2021 to January 2023. Participants were interviewed using a narrative method that invited them space to tell their bereavement stories with little interruption from the interviewer (Kim, 2016). Following a brief demographic survey, participants were asked to share the story of their experience with MAiD and MAiD bereavement in their own words. During this initial stage, the interviewer followed Janesick's (2010) advice to "be still, be quiet, and let the story emerge" (p. 97).

Following the initial presentation of the participant's story, the interviewer asked follow-up questions. An interview guide helped structure these questions, often asking participants to clarify details, elaborate on topics, or provide additional context to better understand the story. The interview guide was an adapted version of a guide published by Beuthin and colleagues (2022). Following this process of narrative interviewing allowed the interviewer to co-construct narrative data with the participant (Janesick, 2010; Kim, 2016). All interviews were conducted and transcribed by the first author.

Data Analysis

The interview transcripts were translated into short stories highlighting the participant's conceptualization of the relationship between dignity and MAiD. The short stories were constructed and analyzed using critical approaches to narrative inquiry (McCormack, 2000a, 2000b, 2004; Souto-Manning, 2012, 2014).

Data analysis was based on McCormack's (2000a, 2000b, 2004) process of interpreting, representing, and storying stories. The crisis of representation (Denzin & Lincoln, 1994) and the associated linguistic turn in post-structural qualitative research (Berbary, 2019) led to novel methods of analysis and interpretation that view knowledge as "situated, constructed, transient, partial, and provisional;

characterized by multiple voices, perspectives, truths, and meanings and a tolerance for paradox, contraction, and paradox" (McCormack, 2000a, p. 4). Instead of breaking the transcripts into codes and themes, we sought to maintain the "contextual, structural, and performance aspects of language" and ensure that we did "not write research participants out of their lives" (McCormack, 2000b, p. 15).

Following McCormack's (2000a, 2000b, 2004) method of storying stories, we transformed the participants' interview transcripts into interpretive stories that represent how they talk about dignity in relation to MAiD. These stories are constructed using participants' words as they appear in the transcript, verbatim, with small changes made to protect the anonymity of participants. The stories do not capture everything that was spoken about in the interviews; rather, they focus specifically on the question of how participants talk about dignity in relation to MAiD. Using McCormack's (2000a; 2000b) multiple lenses of active listening, narrative processes, language, context, and moments, we assembled the transcripts into stories that focused on dignity. The stories were returned to each participant for feedback and approval. Presenting the data as stories rather than extracts from the interview transcript allows readers to understand the situated and complex nature of the participant's experiences in a concise story with a beginning, middle, and end in a format that is engaging and encourages participation in data interpretation (McCormack, 2000b; 2004).

Narrative analytic approach

The short stories were analyzed using critical narrative analysis (CNA) (Souto-Manning, 2014a, 2014b) to explore the narratives that participants used in their stories about dignity and MAiD. CNA is a hybrid methodology marrying narrative analysis and critical discourse analysis that provides a lens for examining how institutional discourses are weaved into everyday stories about personal experience. Institutional discourses, also referred to as power discourses, refer to ordered systems of knowledge that mediate the relationships between people, the world, and practices of meaning making (Foucault, 1978). They influence our experiences, interactions, and ways of knowing and speaking about the world (Burchell et al., 1991). Critical discourse analysis traditionally investigates speech from a top-down, macro perspective, while narrative analysis explores practices of storying and meaning making from a bottom-up micro positioning (Souto-Manning, 2014).

From this perspective, when individuals construct narratives about their lived experiences, they do so by taking up culturally and socially embedded ways of thinking about and knowing the world. However, in their stories, individuals also engage in processes of "questioning and refuting institutional discourses which may be found in these very narratives and oppressing their very lives (or at least being used to justify such oppression)" (Souto-Manning, 2014, p. 177). Exploring participants' stories of MAiD and MAiD bereavement provides readers with an opportunity to witness participants' suffering and understand the experience through their perspectives (Frank, 2016). Using CNA allowed us to explore the relationship between institutional discourses and everyday storytelling about MAiD, bereavement, and dignity.

Ethics

Participants signed consent forms, were sent the interview guide in advance, were assigned pseudonyms, and the details of their stories were changed to protect their identities. The stories were returned to participants for feedback and approval (McCormack, 2000b, 2004). Research Ethics Board approval was obtained from the University of Toronto.

Findings

Family members with complex MAiD bereavement spoke about dignity using three main narratives: 1) the Dignified MAiD Narrative, 2) the Traumatic MAiD Narrative, and 3) the Unjust MAiD Narrative. Each of these three narratives appeared with equal frequency in the data. Four participants' stories aligned with the Dignified MAiD Narrative, four with the Traumatic MAiD Narrative, and

four with the Unjust MAiD Narrative. Eight of the participants spoke about dignity explicitly in their stories, and four participants did not refer to the term dignity specifically. In this section, we present three short stories assembled from the interview transcripts of three participants: Karla, Evan, and Louise. Each story represents a distinct perspective on MAiD and dignity. These three stories were selected because of the way each spoke about dignity with great depth and detail.

The Dignified MAiD Narrative

"You Gave Her a Gift":
Karla's Story

She was my unofficially adopted sister who became part of our family as a young woman in the 1960s. She was fantastic and incredibly beautiful. She had been a professional athlete, had done modelling, travelled the world, had lots of boyfriends, and lived a very, very full life. She was always very physically active, but a smoker all her life. About ten years ago, when my husband was very, very ill he used to use a blood pressure meter at home. One of the many times she was over, she said, "let me try that too." She put on the blood pressure meter, and her blood pressure was through the roof. That night, on her way home she needed cigarettes, but she didn't buy them. She stopped smoking, and shortly thereafter, she developed a serious lung disease.

She had a little house and lived in her little house until the very end. She managed her disease for over a decade, diligently doing her exercises every single day. Up until the year before she passed, she was still clearing the snow, working in her garden, and remaining very active. She needed to be in control of her life. She was not someone who liked pity, and she was very strong mentally. She ran the show and managed her disease very, very, very well.

My sister, who works in the medical field, tried to convince her to move into a long-term care facility. Of course, she refused. I said, "look, you have to stop bullying her." For me, whatever a person chooses at the end of their life is their choice. And just because it's inconvenient for us, that's too bad. It's too bad, you can't bully her. She could have sold her house and lived quite well with care, but because of the way she grew up . . . I often find that children who were not able to control their own life who ended up in care need to control their life. They're going to be in charge and no one's going to tell them what to do, and she was very much like that. No one was going to tell her how to run her life.

Eventually, the doctor told her that she had four months left. We did not see her suffer. And she was very good at hiding pain, she would never want to show any signs of weakness, that was her life. She took a fraction the morphine that was prescribed for her and was refusing home care, but there was a lot of paranoia at the end. She thought the pharmacist was cheating her by not giving her the right number. She started having dreams where she was seeing her mother and I guess that's the subconscious sort of telling you you're at the end. At the end, she kind of realized that her mind was playing tricks on her.

She chose to have MAiD in her little house and let us know her wishes for her celebration of life and that she wanted her remains scattered in the ocean. We arranged everything the way she wanted it. When we got there on the day, she lay down on her couch which is where she spent an awful lot of time during her illness. She wouldn't let my sister and myself be in the room, but my brother was there with her. Her last words were, "Oh, this is nice," and then she was gone.

It was easy, it was gentle for her, and it was the right thing to do for her. I felt strongly that it

should be her decision and that it was nice for her. It was what she wanted, it was gentle, it was kind. And the doctor said, "You gave her a gift." And I really feel we did. We were there, and it's influenced my own decision too. If I had a terminal condition, I would probably choose to go that way as well. My husband did not have that choice; he was in palliative care, and there was a lot of suffering for him because 10 years ago, that was not an option. He would have chosen that, but we basically watched him die over the course of five hours. And prior to that, there was a lot of pain and discomfort. My husband was in and out of the hospital many times and he'd say, "I don't want to die in a hospital." He'd check himself out even though he was super sick; he'd say, "I don't want to die like a dog in the corner." In a physical end-of-life scenario, it's the kind thing to do. There's no dignity in suffering, there's no dignity in that.

There's no dignity in suffering, and this has a lot more dignity to it.

It was a positive experience, she slipped away so peacefully. She was in her own home, we were there, she was comfortable, she was surrounded by people who loved her. It was a positive experience. It was gentle, it was so easy for her. It's a way to say goodbye and it really helped with the grief process. We didn't see her suffer and gasp for breath. It was kind. it was a kind thing to let her go that way. I'm glad that she could choose how she would leave.

Analyzing Karla's story

Karla's account of her friend's MAiD death reflects the Dignified MAiD Narrative that suggests MAiD is a compassionate practice that provides individuals with autonomous control over their own suffering at the end of life.

Karla presents MAiD as a kind and gentle way of ending one's life in the face of a terminal illness, a means of avoiding unnecessary suffering. Karla uses the following words to describe the experience: positive, easy, peaceful, comfortable, kind, gentle, a gift, and dignified. She highlights the correlation between her friend's lifelong personality traits of being independent and having control over her life, and her decision to receive MAiD. Her friend had been sick for over a decade and had been managing her disease well on her own with some help. She is positioned as an independent and capable person who diligently cares for her health. She did not show weakness, would not let others witness her suffering, would not accept home care, and refused to leave her house for long-term care. She exemplifies good management of the self through independence, self-sufficiency, and control of her body, her health, and her environment. She is portrayed as someone who was in control of her life and, through MAiD, was able to control her death.

Karla's positive experience with her friend's MAiD decision is presented in contrast with her experience of her husband's death 10 years prior. Her husband, who was not able to access MAiD, as it was not yet legal, is described as slow, painful, suffering, in discomfort, and without dignity. Her husband was also unable to control the time and place of his death, leading to additional pain and suffering.

The Traumatic MAiD Narrative

"This is Pretty Traumatic Stuff": Evan's Story

In the initial meeting, the doctor let us know how the process would work and what to expect the day of. He'd set up in our minds a kind of romanticized notion of how MAiD works. The family gets together, and somebody puts on a pot of coffee, and there are some refreshments. People tell some stories and say their final goodbyes. There are hugs and kisses, and then the drugs are administered. There's a peaceful goodbye, then there's a bit of mourning, and then the funeral home shows up. He set it up

to be like this peaceful in-control day that is the way the dying person wants it to be instead of the, you know, unpleasant death people are trying to avoid. Well, I'll tell you the reality of that day was kind of anything but; it was chaos.

The nurse was very experienced, but when she tried to find a line, it took her forever. Over this last week when my brother was starting to go downhill, I hadn't appreciated that he was starting to get dehydrated. When the doctor showed up, he called EMS as those guys are experts at getting access in the field. They finally get two lines going, but it's a real panic at that point. There's my brother writhing in pain every time they prick and poke him trying to get access. Which is shocking to me, right? Here's a guy who's on immense doses of opioids, he should be drugged out of his mind, yet each of these pinpricks to try to get access is still torture to him. There are eight people crammed around him, plus two paramedics trudging around our small, beautiful home in their muddy boots. Finally, the doctor's like, "Let's get this going, let's do it now, now, now." My brother is grimacing in pain, eyes half open, complaining like just get this done, get this done.

So, the doctor explains what's going to happen. He's like, "Okay, I'm going to start pushing these drugs, and within about five seconds you're going to relax and go to sleep." He starts to push the drugs, and as you can imagine, from the time you push the plunger on a syringe it takes a while for the empty tubing to fill up before it gets to the patient's arm. So, five seconds pass and it hasn't even reached his arm yet, and my brother says angrily and impatiently, "It's been five seconds." And those are his last words ever. My brother's last words weren't a peaceful, "I love you too," or "See you on the other side," or "It's been great." Nothing like that, no.

His last words were, "It's been five seconds," in a really irritated way.

The doctor and nurse filled out their mountain of paperwork. We called the funeral home, and they sent a couple of guys who took him away. What was left behind were these muddy footprints on our hardwood and various detritus scattered about, including an overflowing garbage can of rubber gloves and vials and things. The next day, I even found some stuff lying in the street where the ambulance had been parked.

For the first few months, we really felt traumatized by that day. Like my wife and daughter were off in the corner as they were pushing these meds, just sobbing and sobbing. I'm thinking, should a teenager even be witnessing this? This is pretty traumatic stuff. And when people asked us about it that was the word that we used a lot; we would say "We're still recovering from the trauma of it." A few months of me sitting on the couch looking over at that spot where the recliner had been, reliving the moment. It wasn't the kind of serious PTSD that needed treatment—my therapist and I agreed on that—but it was a trauma, and it took a couple of months to get over it.

When my mom died, I knew it was a good death in a way. With my brother . . . MAiD is supposed to be a good death, but with the combination of all that, including the way MAiD went down the day of and the friction in the days leading up to it, it wasn't a good death; it was a traumatic death. My brother waited a week or two too long. He was just in immense suffering that couldn't be alleviated by that point. And if your whole point in choosing MAiD is to avoid getting to that spot of losing your dignity and losing control, if that's your goal, then don't wait until you've lost all those advantages. The doctor told me that he was so weak and so sick at this point that he didn't know how much longer he would have lasted anyway. He might have died in another week or two.

> This isn't easy, this sounds like an easy out, and death is not easy, death is hard, death is ugly. You're still going to grieve the same, possibly worse because it ends up feeling a bit unnatural. So, I guess I would warn that while MAiD may be a humane way to avoid the worst of human suffering, it's not a panacea; it's not an easy way out. At least it wasn't easy for me, and in the end, it wasn't easy for my brother, because I think he left it way too long.
>
> I wish medical professionals could have warned me of the fact that that day might not be this wonderful peaceful romanticized departure, but that it might be traumatic. I had envisioned a nice slow-paced day; it's this dignified thing. There was nothing dignified about it; it was a disaster, an unmitigated disaster.

Analyzing Evan's story

Evan's experience of his brother's MAiD death represents what we call the Traumatic MAiD Narrative. We conceptualize this narrative as opposing or contrasting to the Dignified MAiD Narrative. Instead of experiencing MAiD as being a gentle, kind experience that alleviates suffering, MAiD may be experienced as a traumatic event for some family members. It may be disorganized, rushed, or chaotic. Evan states that the MAiD provider had set up the expectation for the family that MAiD would be a peaceful, controlled, and affectionate event that included the gathering of family and an opportunity to say goodbye peacefully. This expectation reflects the Dignified MAiD Narrative discussed in the previous section. Evan considers this to be a romanticized notion of MAiD that set up false expectations regarding what the day would look like.

Evan described the MAiD event in no uncertain terms, calling it a "chaotic" and "an unmitigated disaster." Evan used even stronger language during the interview but chose to remove the profanity in the published version of the story. He shared how the nurse's inability to successfully set up an intravenous line, where the life-ending medications could be administered, led to a chaotic scene where paramedics were called to assist. This process was not only stressful but physically painful for his brother who was suffering from extreme pain despite the high doses of opioids he had been prescribed. Once the lines had been established, there was a sense of urgency on the part of both the physician and the patient to quickly complete the procedure. This urgency and irritation resulted in his brother's last words: "it's been five seconds." Evan repeated this phrase several times highlighting its salience to his overall experience of the event. Evan suggests that the events may have transpired differently had his brother not waited so long to schedule the date, and had he not been dehydrated. He acknowledges that a confluence of factors led to the day feeling out of control and that if it had happened sooner, things might have gone smoother.

Evan's categorization of his brother's MAiD as not a good death, but a traumatizing death, further contrasts the Dignified MAiD Narrative with the Traumatic MAiD Narrative. Evan explains that both he and his family experienced the MAiD event as a trauma that took months to recover from. In contrast to Karla who described her friend's MAiD as easy and peaceful, Evan says that his brother's MAiD was not easy; it was a hard and ugly death. He also explains that his grief following the event may have been worse because something felt unnatural about the event. It was not the romanticized, peaceful death that the physician had promised them. Instead of bringing comfort, that unrealized expectation may have caused harm.

The Traumatic MAiD Narrative represents a departure from the dignified vision of MAiD promoted by some medical providers and activist groups. This is not to suggest that MAiD was not the right decision for Evan's brother or that he should not have access to this option. Rather, patients and families should be given realistic expectations for what to expect on the day and should be provided with information regarding how to ensure patients are prepared for the procedure. Evan's story displays how family members with chaotic MAiD experiences may view the event as undignified, and it may not align with the qualities ascribed to a good death.

The Unjust MAiD Narrative

"Dignity is Not Solely in the Choice Alone": Louise's Story

We had both travelled to the same clinic in the United States (US) to get treatment for our chronic illnesses. We couldn't stay in the US past six months, and we had all paid out of pocket to the tune of at least 100 grand each for our treatment. He ran out of cash, the same as we all did, and went back to Canada. I think he left with high hopes that the doctors in Canada would look at all of these test results from the US with a fresh set of eyes, but they never did. That never happened, and they refused to even acknowledge the fact that this chronic illness was part of it. He just went downhill once he got home. It got so bad that he chose MAiD.

I don't judge him; I don't judge anyone for choosing MAiD. The part that I have a real problem with is the fact that I fully believe if he had had access to reasonable, responsible healthcare, appropriate healthcare, he wouldn't have chosen it. Because I saw him fight so hard to live. He was the toughest mo-fo I ever met and he never complained. I still wrestle with the fact of, what kind of place was he in to have to make that decision? Because I know he wouldn't have otherwise if he had had the proper care. And he tried to get it, and no one was listening, and that's what I've always had a problem with. And so that's the part about it with MAiD that I take real issue with.

I'm not mad at my friend, I'm mad because he didn't get the healthcare he should have gotten. This whole dying with dignity thing, this is not it. I don't know why people think that you can't have a death with dignity that isn't pre-emptive. It's dignity if it's someone's choice. If the doctors are saying, you have stage four cancer, and there is nothing else we can do for you, then I can get on board. But that was not the case with my friend. So that's where I really see a huge gap, and I really don't believe he's the only one.

I've taken care of so many patients, and their families as they died that I would still say is a dignified death. I have heard this from patients I've taken care of as they're dying because when you're a hospice therapist, you're like a bartender, everybody tells you everything, right? It's great, I love the intimacy part of it. I've seen good deaths, I've seen bad deaths and everything in between. So, I feel pretty qualified to talk about that. I just really believe that people need to have access to appropriate care. This decision shouldn't have to be made because you don't have access to care.

Just because someone is choosing to die doesn't mean it's with dignity, because what is behind the choice that is being made? I fully believe dignity is not solely in the choice alone. Dignity comes from the reasons that you're making the choices. When you can make the decision because you feel you have the support, the accessibility, whatever resources you need, and it's a choice that is unencumbered by financial constraints or feeling like you're a burden on your family, or because you're afraid that you're not going to have access to appropriate pain medication, for example. When you can make a choice to die and know, and fully understand, what's going to support you in that process, that's dying with dignity.

My question is, how many out there are truly dying with dignity? How many out there are making choices based on believing they have what they need versus a lack of something? And I feel that's the big gap. If someone's choosing it because they can't endure their life circumstances, I'm not going to judge someone for that, I just feel that it's really important to make sure that they have supports in place so they can make an informed choice. And how could

it be an informed choice, informed consent, if the supports are not there? Right? I don't think not being able to afford to live, or find housing, should be reasons to choose to end your life. I feel that it's a huge failure. I don't even see it as constitutional in Canada. How is that even supportive of the Charter of Rights and Freedoms, for Christ's sake?

There is no dignity- there's no dignity.

This grief feels different because there's nowhere to go with it. There's nowhere to put it. There's nowhere to talk about it. There's nowhere to share it. You talk about someone dying of cancer that's very much accepted, and there's a lot of empathy and compassion. When it comes to MAiD, there are so many questions. And when I tried to answer my friends and family's questions, I felt there was judgement on me, misunderstandings, and miscommunication. I was so angry talking about the failures of the healthcare system that people started thinking I was a conspiracy theorist or something. I felt like people were saying, shut up, Louise, you're being too much. In my mind, that's what it felt like.

Analyzing Louise's story

While Karla and Evan's stories about dignity focus primarily on the experiences of their loved ones who chose MAiD, Louise takes a broader perspective in her discussion about the relationship between dignity and MAiD. In sharing her story, Louise used a disability justice approach to critique the social, political, and medical institutions that undermine informed choices. She speaks from her experience as a healthcare professional, an advocate for better treatment of Canadians with chronic illnesses, a person with a disability, and the friend of someone who has chosen MAiD. These intersecting identities and experiences converge in her story and reflect what we call the Unjust MAiD Narrative.

Louise argued that choosing to die pre-emptively does not inherently produce a good or dignified death. Dignity comes from the ability to make informed choices between legitimate and appropriate care options. Through her story, Louise presents an ethical argument that individuals living with chronic illness who lack access to appropriate care, financial resources, adequate housing, social support, or necessary medication may face constrained choices regarding MAiD, rather than truly free decisions. Louise identifies these multiple systemic issues and asks: why are people with disabilities making that choice?

We label this narrative the Unjust MAiD Narrative because participants who employed this line of reasoning in their stories suggest that people with disabilities are not treated with dignity in the Canadian healthcare system. Participants described how they believe the state provides the consolation of a "dignified death" to remedy the indignity they are forced to experience in their lives. Louise relays how she believes her friend chose MAiD because he did not have access to reasonable, responsible, and appropriate healthcare in Canada.

Louise described the challenges she has encountered in receiving support to manage her grief over her friend's death. The anger and criticism she expressed toward the healthcare system were not acceptable in her social circle. When she shared her feelings with those close to her, she felt judged and silenced. Louise describes the indignity of having the choice to die which might be attractive to those with limited access to healthcare, who face oppression in an ableist society, and lack the social supports necessary to have an acceptable standard of living. From Louise's perspective, it is an indignity to have one's life choices constrained by structurally oppressive forces.

Discussion

We conducted this research with family members with complex MAiD bereavement experiences using a critical narrative inquiry approach and explored how family members discuss dignity in their stories about MAiD and MAiD bereavement.

Frank (2016) writes that we use stories to make sense of our lives. We carry them and their allegories with us like companions. It is important for the discipline of bioethics to attend to stories, which "show us where the line is between what is permissible and impermissible, and what is at stake in crossing that line" (Frank, 2016, p. 17). Stories provide people with a container to hold, understand, and share their suffering with others. We are grateful that the participants in this study were willing to share their stories with us.

Family members with complex MAiD experiences draw upon three main narratives when discussing the relationship between MAiD and dignity: the Dignified MAiD Narrative, the Traumatic MAiD Narrative, and the Unjust MAiD Narrative. Through the three short stories presented above, we examined how the institutionally privileged Dignified MAiD Narrative can cause harm to individuals whose experiences do not align with this narrative. The Dignified MAiD Narrative brought Karla peace and closure, helping her close friend avoid what could have been a painful death. In Evan's story, we examined how the Dignified MAiD Narrative set up false expectations, or a romanticized notion, for a MAiD experience that was nothing like the traumatic experience that occurred on the day of his brother's death. And in Louise's story, we witnessed how this narrative prevented her friends from being able to adequately understand her experience and her concerns and provide her with support. Louise felt silenced because her story of MAiD bereavement did not align with the institutional discourses presenting MAiD as an autonomous, informed choice.

The Dignified MAiD Narrative resonates with notions of a "good death" that reflect the values of "privacy, dignity, independence, personal growth and informed choice" (Walter, 1994, as cited in Karsoho et al., 2016, p. 5). The conceptions that MAiD is a dignified death and that MAiD is a good death can be deconstructed using a technique that Rose (1993) describes as a style of thought; "a way of seeing, a way of explaining, a way in which reasoning is embedded within certain practical and intellectual techniques . . . it is about what counts as an explanation, and it is also about what there is to explain" (p. 412). The Dignified MAiD Narrative is aligned with individualism and a western conception of individual autonomy. The Dignified MAiD Narrative affirms a particular kind of life, that of freedom, choice, and dignity. In doing so, it also affirms MAiD as a good death.

It is interesting to consider this finding in light of Louise's story, given that she did not find her experience resonated with the notion that MAiD represents a dignified, good death. As a result of this misalignment, Louise's suffering was unacknowledged. This reflects findings from a previous study where we described how unacknowledged emotional pain related to MAiD bereavement can result in disenfranchised grief (Serota et al., 2023). As with any medical procedure, in rare cases, MAiD can have complications. A retrospective cohort study of 3557 MAiD deaths in Ontario found that complications occurred in 1.2% of cases (Stukalin et al., 2022). The most common complication was "problems obtaining intravenous access or loss of intravenous access after the MAiD procedure was started (23 cases)" (p. E22). Difficulty obtaining or maintaining intravenous access has also been noted in Zworth and colleagues' (2020) scoping review, representing 4/22 of the intravenous administration complications they reviewed. Witnessing such complications may be rare; however, they can cause significant distress to family members (Stukalin et al., 2022). Evan's story provides further evidence for this finding. Future research should continue to investigate the impact of MAiD complications on witnesses, including family members and healthcare providers.

All three narratives are epistemologically rooted in a biomedical conception of the body that aligns with a medicalized view of death and dying. Medicalization is a term used to describe how an ever-widening range of human experiences become "defined, experienced, and treated as medical conditions" (Barker, 2008, p.21). The North American practice of palliative care has been critiqued for decades for evolving into a medicalized practice of death and dying (Clark, 2002). MAiD, too, is governed by medical and legal powers that make

productive use of the medicalization of death and dying (Broom, 2017; Hannig, 2019; Karsoho et al., 2016; van Wijngaarden & Sanders, 2022; Young, 2020). Hannig (2019) explored the medicalization of dying and the limitations of autonomy available in the context of assisted dying. Although MAiD appears to be a radical act of autonomy, Hannig argued that it is instead a heavily regulated procedure. The regulatory power of the state, its legislation, and the medical knowledge regime that underpins it produce subjects whose end-of-life choices are being regulated by a system that "compels patients to reproduce the proper narratives at the proper time" (Hannig, 2019, p. 68; Lavi, 2005).

Van Wijngaarden and Sanders (2022) have also found that medicalization influences assisted dying discourse in the Netherlands. In line with this previous research, we find that the choice-repertoire reflects a similar discursive construction of autonomy as the Dignified MAiD Narrative identified in our study. In this dominant representation of good death, dignity was constructed as being an important aspect of choice, control, and autonomy at the end of life.

They write,

> At first sight, the choice-repertoire challenges the power of medicine by constructing curative medicine (with its focus on life prolongation) as a producer of extended suffering at the end of life. The right to choose the time and manner of death is constructed as safeguarding people from being kept alive too long and enabling a dignified death. Simultaneously, and paradoxically, this 'solution' depends at least in part on medical means and assistance (van Wijngaarden & Sanders, 2022).

We posit that the Dignified MAiD Narrative is one such narrative that the medico-legal system encourages family members to take up. The view of MAiD as an autonomous action may remove a perceived burden from family members, who otherwise may have to choose to end someone's life, for example, through the withdrawal of life-sustaining treatment. Family members may have to live with the responsibility for such actions, even if the decision is consistent with their loved one's best interests and stated values. Considering the choice-repertoire in the context of Evan's story about his brother's MAiD experience highlights the complexities of end-of-life decisions. Although having the option of MAiD did not completely prevent suffering at the end of his brother's life, it may have curtailed prolonged, intolerable suffering. From Evan's descriptions of his brother's suffering, it is evident that he was in an immense amount of pain during the final weeks, days, and minutes of his life. MAiD may not prevent people from being "kept alive too long" (van Wijngaarden & Sanders, 2022) and MAiD deaths can be chaotic, undignified, and traumatic for the family members who witness them.

Limitations and future research

This study investigated the experiences of Canadians who had complex MAiD bereavement experiences, reporting there was some disagreement, family conflict, or differences in understanding about MAiD. Thus, the findings regarding how individuals talked about dignity may not reflect the experiences of those without complex experiences. Future research should investigate how family members with a variety of experiences speak about dignity in relation to MAiD. Researchers should continue to investigate how MAiD complications can impact family members witnessing the procedure. All participants identified as white and of European descent, and all interviews were conducted in English. Future research should seek to document the stories and experiences of more racially, ethnically, and linguistically diverse Canadians. Future research should continue to explore the relationship between MAiD and dignity, including a historical investigation into the philosophical and epistemological antecedents of this style of thought (Rose, 1993).

Conclusion

In this investigation into how family members with complex bereavement experiences following MAiD talk about dignity in relation to assisted dying, we found that family members draw upon three narratives: the Dignified MAiD Narrative, the Traumatic MAiD Narrative, and the Unjust MAiD

Narrative. We explored how the Dignified MAiD Narrative represented a dominant social discourse that reflected a medicalized view of death and dying. The Dignified MAiD Narrative may provide solace to family members who agreed with the MAiD decision and witnessed a peaceful provision. However, the prevalence of this narrative may simultaneously create moral tensions by setting up unrealistic expectations for family members. Finally, the Traumatic and Unjust MAiD Narratives provide counter perspectives that challenge the notion that MAiD leaves a legacy of a dignified, good death.

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