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Disability, Sovereignty, and the Politics of Death: Interpreting MAID (Medical Assistance in Dying) Through a Critical Disability Studies Lens

Handicap, souveraineté et politique de la mort : interpréter l'AMM (aide médicale à mourir) à travers le prisme des études critiques sur le handicap

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Abstract

If there is nothing natural about death, in what ways do we socially organize death? Given that disability is regarded as a memento mori, what might disability studies tell us (i.e., what can we learn) about this social organization of death through interpretive disability studies methods? How does our language reveal and represent the appearance of death and the ways in which death is socially accomplished, limited, and made possible within the context of cultural knowledge production? Achille Mbembe tells us in his work *Necropolitics*: "sovereignty means the capacity to define who matters and who does not, who is *disposable* and who is not" (Mbembe 2019 [2003], 80 [27]). How does our knowledge production speak to the power and capacity to define the value of people into socially constructed, "self-evident categories" (Kafer 2013, 10) and what are the consequences of limiting the possibilities for expanding our concepts that designate the meaning of a human life—specifically within the context of Health Canada's (2024) *Fifth Annual Report on Medical Assistance in Dying in Canada, 2023.* This paper considers how we, in contemporary Western society, interpret the meaning of death through close reading analysis of select cultural representations that ask us to consider: (i) the ways in which death might be socially accomplished, and (ii) how our words—our language—limit the possibilities of death. In this way, we might begin to reveal and examine normative conceptions of life, death, and disability—to consider the ways in which our concepts require expansion.

Résumé

Si la mort n'a rien de naturel, de quelles manières la structurons-nous socialement? Étant donné que le handicap est souvent perçu comme un *memento mori*, que peuvent nous révéler les études sur le handicap quant à cette organisation sociale de la mort, notamment à travers des méthodes interprétatives propres à ce champ? Comment notre langage donne-t-il forme à l'apparition de la mort, tout en exposant les façons dont elle est socialement accomplie, limitée et rendue possible dans le cadre de la production culturelle du savoir? Achille Mbembe écrit dans la revue *Necropolitics* : « la souveraineté signifie la capacité de définir qui compte et qui ne compte pas, qui est jetable et qui ne l’est pas » (Mbembe 2019 [2003], 80 [27]). Comment notre production de savoir reflète-t-elle ce pouvoir de catégoriser la valeur des individus dans des « catégories évidentes » socialement construites (Kafer 2013, 10), et quelles sont les conséquences de cette limitation sur notre capacité à élargir les concepts qui définissent la valeur d’une vie humaine — en particulier dans le contexte du *Cinquième rapport annuel de Santé Canada sur l’aide médicale à mourir au Canada, 2023* (publié en 2024)? Cet article examine la manière dont, dans les sociétés occidentales contemporaines, nous interprétons le sens de la mort à travers une analyse approfondie de certaines représentations culturelles. Ces dernières nous invitent à réfléchir : (i) aux modalités par lesquelles la mort peut être socialement accomplie, et (ii) à la manière dont notre langage restreint les possibilités de penser la mort. Ce faisant, il devient possible de dévoiler et d’interroger les conceptions normatives de la vie, de la mort et du handicap, et d’envisager les transformations nécessaires de nos cadres conceptuels.

Keywords

Disability Studies; MAID (Medical Assistance in Dying); Necropolitics

Mots-clés

Études sur le handicap; AMM (aide médicale à mourir); nécropolitique

Introduction

If there is nothing natural about death, in what ways do we socially organize death? Given that disability is regarded as a memento mori,[1] what might disability studies tell us (i.e., what can we learn) about this social organization of death through interpretive disability studies methods? How does our language reveal and represent the appearance of death and the ways in which death is socially accomplished, limited, and made possible within the context of cultural knowledge production?

Achille Mbembe tells us in his work *Necropolitics*: "sovereignty means the capacity to define who matters and who does not, who is *disposable* and who is not" (Mbembe 2019 [2003], 80 [27]).[2] I wonder how knowledge production processes speak to the power and capacity to define and assign value to a person's life in such a way that socially organizes people into socially constructed "self-evident categories" (Kafer 2013, 10). I also wonder about the consequences of limiting the possibilities for expanding our concepts that designate the meaning of a human life—specifically within the context of Health Canada's (2024) *Fifth Annual Report on Medical Assistance in Dying in Canada, 2023*.

Although Achille Mbembe does not explicitly state that their work *Necropolitics* (2019 [2003]) makes use of an interpretive disability studies perspective, I will nonetheless

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[1] (T. Titchkosky, personal communication, November 20, 2024).

[2] Please note: Achille Mbembe published two works under the title: *Necropolitics* in the years 2003 and 2019. In 2003, Achille Mbembe's paper titled *Necropolitics* (translated from French into English by Libby Meintjes) was published with *Public Culture*. In 2016, Mbembe's book titled *Politiques de l'inimitié* [Politics of Enmity] was published with *La Découverte*. Mbembe's book *Politiques de l'inimitié* was translated from French into English by Steven Corcoran (in the year 2019) under the title: *Necropolitics* (published with *Duke University Press*). This 2019 work (unlike the 2016 work) includes the original *Necropolitics* (2003) essay. For clarity, the in-text citations included in this paper will reference the English translation of *Necropolitics* (Mbembe 2019) as translated by Steven Corcoran. Where translations align, page numbers for both 2003 and 2019 publications will be provided.

be reading Mbembe's insights as a framework that aids my exploration into how we might begin to better understand our social orientation in relation to the "natural attitude" (Ahmed 2006, 549) (understood here as culturally constructed narratives and perceptions that often remain unquestioned). This paper considers how we, in contemporary Western society, interpret the meaning of death through close reading analysis of select cultural representations that ask us to consider: (i) the ways in which death might be socially accomplished, and (ii) how our words—our language—limit the possibilities of death. In this way, we might begin to reveal and examine normative conceptions of life, death, and disability—to consider the ways in which our concepts require expansion.

Adapted from Tanya Titchkosky's exploration into "disability-perception" this work follows a similar line of inquiry and asks the following question: "In what ways might attention to [death][3] as an interpretive act inflect social inquiry" (Titchkosky 2024, 1)? By making use of a disability studies perspective and interpretive methods (understood here as a social activity) this analysis considers the ways in which people engage with the "activity of *perception as interpretation*" (Titchkosky 2024, 1) as a way to pursue the necessary act of *hesitation* (Al-Saji 2014). A moment of hesitation supports the need for considering the creation of our socially constructed categories (and patterns of thought) that we so often fail to question and appear to accept as *natural*.

Through a disability studies perspective and interpretive methods, this analysis aims to create moments for *hesitation* (Al-Saji 2014) that invite critical reflection of the

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[3] Please note: Tanya Titchkosky's article explores "dyslexia as an interpretive act [that] inflect[s] social inquiry" (Titchkosky 2024, 1). I substitute *dyslexia* with *death* for the purpose of my exploration in this paper.

stories we tell, retell, accept, and reinforce the socially constructed narratives (i.e., appearances) of death, "*death-worlds*" (Mbembe 2019 [2003], 92 [40]) and the possibilities of new human categories, namely, "the status of the *living dead*" (Mbembe 2019, 92). I wonder about the ways in which the language we use when we speak of life, death, and disability shapes the ways in which life, death, and disability appears and disappears (Titchkosky et al. 2022) specifically within the context of contemporary Western society. Following Titchkosky's article, *Interpretive Methods in Disability Studies: Dyslexia Inflected Inquiry*, this paper begins to wonder about the ways in which (i) we (as human beings) relate to one another, (ii) the "normative order" (Titchkosky 2024, 1) organizes a collective consciousness, (iii) the realms of environment, interaction, and "knowledge production" (2024, 2) connect, influence, and shape one another. Such connections may very well have something to teach us about the cultural consciousness, and the ways in which we formulate meaning of that which is given in-between these representations of life, death, and disability through "the social activity of interpretation" (2024, 1).

Health Canada's (2024) *Fifth Annual Report on Medical Assistance in Dying in Canada, 2023*

The following short account of death belongs in the interpretive framework of MAID (Medical Assistance in Dying) and makes use of the statistics published by the Government of Canada on December 11th, 2024. The first paragraph written in Health Canada's (2024) report provides the following sentiment that orients our perceptions toward understanding Health Canada's positionality in relation to its "commit[ment]" and "responsib[ility] for helping the people of Canada" (Health Canada 2024, 1):

> Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health. Health Canada is committed to improving the lives of all of Canada's people and to making this country's population among the healthiest in the world as measured by longevity, lifestyle and effective use of the public health care system. (Health Canada 2024, 1)

This sentiment reveals Health Canada's cultural values, beliefs, and priorities. Health Canada values and prioritizes the making of a healthy population "as measured by longevity, lifestyle and effective use of the public health care system" (Health Canada 2024, 1). What implications can we draw from this sentiment? There is an air of competition layered within Health Canada's commitment towards achieving a high global rank reflecting a healthy population. In this way, Health Canada has provided a rationale, a method, and a clear goal—all of which steer the social organization of achieving health. The appearance of health is accompanied by an appearance of death (i.e., a *lack* of health). The following excerpt, section 2.1 of Health Canada's (2024, 14) report, provides an overview of the Government of Canada's accounts of the 2023 MAID requests and outcomes as reported by Health Canada (2024, 14):

> 2.1 MAID requests and outcomes
> This report details 19,660 reports of MAID requests that Health Canada received in 2023. There were 15,343 people who received MAID; the remaining cases were requests for MAID that did not result in MAID being provided (2,906 died before receiving MAID, 915 individuals were deemed ineligible and 496 individuals withdrew their request). (Health Canada 2024, 14)

Interpreting the Numbers

This report provides a quantifiable, numerical representation that accounts for Canada's achievement of death (specifically:15,343 deaths by MAID in 2023) indicating that 78.04% of requests were deemed eligible. This report discloses that 4.65% of all requests "did not result in MAID being provided" as these "915 individuals were deemed ineligible[.]" A total of 2.52% "withdrew their request" and a total of 14.78% "died before receiving MAID" (Health Canada 2024, 14).

How is this short account of death socially organized and how do these words accomplish and limit the possibilities of death? The statistics outlined in section 2.1 (MAID requests and outcomes) of this report reveal some insight in relation to the limits, possibilities, and accomplishment of death through a categorization process. Such a categorization process requires parameters that guide the process of interpreting an individual's request. The individual is deemed eligible or ineligible to receive MAID. Such an eligibility process presumably considers a variety of factors and criteria that seek to determine an individual's eligibility (or ineligibility) to access (and accomplish) death by MAID.

Would such interpretations perceive the eligible category as a category of individuals who have *successfully* achieved death? Does such a perception interpret the ineligible category as an *unsuccessful* population in some fashion? If so, we might understand section 2.1 (MAID requests and outcomes) as a detailed account outlining the country's success rate in relation to the achievement of death belonging to the interpretive framework of MAID.

Canada's methods for deploying "effective use of the public health care system" (Health Canada 2024, 1) resulted in 15,343 medically assisted deaths in 2023. Through the social act of interpreting people into categories (specifically, *eligible* and *ineligible*) Health Canada rears a high success rate (78.04%) among MAID applicants in 2023, with a small margin in which death is limited (as reflected in the 4.65% of MAID applicants deemed ineligible). This rate of achieving death prompts the following question: How do we interpret the data presented within section 2.1 MAID requests and outcomes? How do we understand outcomes in relation to socially organized categories (specifically, eligible and ineligible, successful and unsuccessful)? Does this report represent the ways in which we might engage with death (and achieve death) through the "effective use of the public health care system" (Health Canada 2024, 1) in such a way that prioritizes and contributes to the making of a healthy population?

I wonder how Health Canada interprets the use of MAID. Perhaps Health Canada understands the use of MAID as an example of how Canadians might (i) make "effective use of the public health care system", and (ii) actively contribute to Health Canada's "commit[ment]" in "making this country's population among the healthiest in the world" (Health Canada 2024, 1). Such an interpretation prompts additional exploration into the ways in which we understand (and define) health through the presence of death.[4]

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[4] Health Canada (2024) notes the following statistic: "MAID was provided to 15,343 individuals in 2023 [...] Based on previous reports, there were 44,958 MAID provisions since its legalization in 2016 to 2022, which brings the total number of MAID provisions in Canada to 60,301." (Health Canada 2024, 15)

The MAID Regime: A "Humane and Progressive" Achievement of Death

The *Canadian Journal of Disability Studies* published a special issue titled *Medical Assistance In Dying: Resistance in Canada* wherein Catherine Frazee (2024) presents a rationale for this work and poignantly highlights the significance of counter-narratives:

> Tomorrow's historians will find rich veins of meaning in the crush of narrative and counter-narrative that swirl around Canada's controversially named 'Medical Assistance in Dying' (MAID) regime. Expanded in March 2021 to authorize medical practitioners to administer euthanasia or suicide assistance[5] to disabled persons who are still very much alive and in no way approaching the end of their natural lives, the regime has been championed in public policy debates as progressive and humane [...] Whose voices will prevail when the story of MAID is written? (Frazee 2024, 1)

How are these words narrating this representation of death? How do these words accomplish and limit the possibilities of death? Catherine Frazee draws our attention to the language and the words we use when we speak of disability, medical intervention, humanity, and death. Framing "euthanasia or suicide assistance" as "progressive and humane" (Frazee 2024, 1) mediates an accomplishment of death as a sensible appearance.

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[5] *What does it mean to authorize medical practitioners to administer euthanasia or suicide assistance?* When administering MAiD to an eligible patient, "The Canadian Association of MAiD Assessors and Providers recommends fixed dosing of midazolam (an anxiolytic), 10 mg; propofol (an anesthetic coma-inducing agent), 1000 mg; and rocuronium, 200 mg, or cisatracurium, 40 mg (neuromuscular blockers to stop respiration)" (Stukalin et al. 2022, E20).

Health Canada (2024) defines “Medical assistance in dying (MAID) [a]s a health service that allows someone who is found to be eligible[6] to receive assistance from a medical practitioner to end their life.” Eligible individuals include those living with “a serious illness, disease or disability” (Health Canada 2024, 6). I wonder about the ways in which we interpret this presentation of access. Given the limited resources made available for disabled people in Canada, how do we make sense of the support available and what sort of orientation is required of us in order to perceive the available resources provided by social assistance and disability support systems (e.g., Ontario Works; Ontario Disability Support Program) as accessible and humane? Are such features of social support (specifically, MAID and provincial disability support programs) perceived (perhaps championed) as “progressive and humane” (Frazee 2024, 1) examples that reflect “effective use of the public health care system” (Health Canada 2024, 1)?

I cannot help but stagger with *hesitation* (Al-Saji 2014) upon reading the first words written inside the *Fifth Annual Report on Medical Assistance in Dying in Canada, 2023*. Health Canada acknowledges its purpose as “the federal department responsible for helping the people of Canada maintain and improve their health” (Health Canada 2024, 1). In fifty-seven words, Health Canada establishes the parameters of its commitment to the people of Canada in clear, direct, succinct detail. Not only does Health Canada reveal its methods for measuring the health of this country’s population, but Health Canada also

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[6] “The *Criminal Code* sets out strict eligibility criteria” and “safeguards to ensure that MAID is safely provided” to eligible patients. “To be eligible for MAID, an individual must”, (a) “be at least 18 years old and mentally competent”, (b) “have a grievous and irremediable medical condition, specifically”, (i) “have a serious illness, disease or disability”, (ii) “be in an advanced state of decline that cannot be reversed”, (iii) “experience unbearable physical or mental suffering from the illness, disease, disability or state of decline that cannot be relieved under conditions that the person considers acceptable” (Health Canada 2024, 6).

reveals its commitment toward achieving a competitive goal (i.e., a prestigious global rank): “to making this country’s population among the healthiest in the world” (Health Canada 2024, 1). Health Canada concludes with disclosing the criteria by which Canada measures (and prioritizes) the collective health of the population.

What can we learn from Health Canada’s opening sentiment?

Health Canada present itself as a responsible and committed institution working towards a greater good for the country’s population. And yet, the final phrase of this sentiment instils a tension that is far from comforting (and much closer to *haunting*). Health Canada discloses the criteria used to measure and assess health—one of which assesses the health of a population by measuring the “effective use of the public health care system” (Health Canada 2024, 1). I cannot help but be reminded of Nancy Hansen’s (2022) concluding insight drawn from her paper, *DisAppearing Disability: Disability MAiD Invisible*: “This discussion is not about numbers, politics, or rhetoric. It is about policies that excuse killing people” (Hansen 2022, 220).

Might Nancy Hansen (2022) and Catherine Frazee (2024) interpret Health Canada’s sentiment as a rationale that excuses the production of policies (specifically, MAID) that achieve death in a “progressive and humane” fashion[7] (Frazee 2024, 1), or is this narrative of death a closed topic for interpretation?

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[7] The following description provided by Dying With Dignity Canada (2024) reveals the three medications (and their effects) used in a MAID provision: (i) *midazolam* “places the patient into a deep state of relaxation”, (ii) *propofol* “place[s] the patient into a deep coma”, and (iii) *rocuronium* “paralyzes the muscles in the body. If the patient hasn’t stopped breathing already, they will now stop breathing. Once the body stops breathing, the organs can no longer receive oxygen and one by one the organs will shut down until the heart finally stops beating and the patient dies” (Dying With Dignity Canada 2024, paras. 1-6). This article was last updated on June 7th, 2024. Dying With Dignity Canada’s article titled

Literature Review

As Catherine Frazee asks us to consider the future discourse of MAID that calls for the voices of disabled people, we must also consider the existing literature that may provide further insight regarding the current "veins of meaning in the crush of narrative and counter-narrative that swirl around Canada's controversially named 'Medical Assistance in Dying' (MAID) regime" (Frazee 2024, 1). Frazee asks: "Whose voices will prevail when the story of MAID is written" (2024, 1)? This literature review offers a space for engaging with the voices of authors whose narratives have already begun to contribute to the writing of MAID's story.

The Truth about Stories: Narratives that Haunt Us

Indigenous scholar and master storyteller,[8] Thomas King (2003) explains the importance of understanding a story in relation to understanding a person, in their book titled *The Truth about Stories: A Native Narrative.* "In order to understand this story [...] it is important to know the People and where they came from and what they went through" (Alexie 2002, 5; as cited in King 2003, 116). King tells us,

> Over the years, I've lost more than my fair share of friends to suicide. The majority of them have been mixed-bloods. Native men and women who occupied those racial shadow zones that have been created for us and that

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Clarification about the medications used in a MAID provision (2024) is available at the following: https://www.dyingwithdignity.ca/blog/clarification-about-the-medications-used-in-a-maid-provision/

[8] See Thomas King's book titled *Indians on Vacation: A Novel* (2020) for a humorous, relatable text filled with rich discussion of current, past, and future social and political issues, including cultural understandings of mental health and depression, as experienced and lived by Indigenous persons.

> we create for ourselves. The latest and greatest loss was the Choctaw-Cherokee-Irish writer Louis Owens, who killed himself in an airport parking garage on his way to an academic conference in Bellingham, Washington. Louis was a fine novelist and an even better literary/cultural critic and theorist. But most especially, he was a good friend, more a brother, really. We were of a like age, shared much the same background, were haunted by the same fears. We loved fly-fishing and the solitude of quiet places. We understood in each other the same desperate desire for acceptance. And we were both hopeful pessimists. That is, we wrote knowing that none of the stories we told would change the world. But we wrote in the hope that they would.
>
> We both knew that stories were medicine, that a story told one way could cure, that the same story told another way could injure. (King 2003, 92)

King's words are profoundly important to the ways in which I understand storytelling and narrative inquiry as methods for engaging with "discursive disability studies"[9] (Goodley 2017, 140). I draw strength from King's notion of *hopeful pessimism*. To write stories knowing that they are unlikely to change the world—but writing them anyway, "in the hope that they would" (King 2003, 92) reminds me why we tell the stories that bring us pain and remind us of what we fear. So often, disability, injury, and death are things that draw the attention of society—a perverse sort of fascination evident in the *stares* of society[10] (Garland-Thomson 2002). I marry this sentiment of hopeful pessimism with Goodley's proposed "discursive disability studies" (Goodley 2017, 140) as a way to structure an analysis that embraces the power of listening and the meanings that might be made through storytelling—particularly as told by the voices of whom the story is about, and

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[9] See Goodley (2017) for further discussion on *discursive disability studies*: "Discursive disability studies push us to think that even something as apparently real, fleshy and physical as the human body has become materialised through discourse (a key argument of Judith Butler)" (Goodley 2017, 139). "We are all the products of a discursive dis/ability society" (2017, 140).

[10] See Rosemarie Garland-Thomson's (2002) work titled, *The Politics of Staring: Visual Rhetorics of Disability in Popular Photography*, for further discussion on the ways in which disability has always been a sight to see, stare at, and watch.

perhaps as a way to better understand within others “the same desperate desire for acceptance” (King 2003, 92). We might discover that we too are “haunted by the same fears” (King 2003, 92) as the one who shares with us their story. The stories we share about difference, death, and suicide can injure—perhaps by eliciting painful or uncomfortable thoughts that we prefer not to think about. I choose to bring these stories to light anyway, in hopes that, as Thomas King and Louis Owens know, “that stories were medicine, that a story told one way could cure” (King 2003, 92). I hesitate to use the word *cure.* Rather, I prefer to consider that these stories were and are the medicine of *hope*.

Different Rights, Different Goals

Achille Mbembe considers how the notion of “cultural imaginaries” construct and assign “meaning to the establishing of different rights for different categories of people, rights with different goals but existing within the same space” (Mbembe 2019, 79). Mbembe tells us,

> The writing of new spatial relations (territorialization) ultimately amounted to the production of boundaries and hierarchies, zones and enclaves; [...] the differential classification of people; resource extraction; and, finally, the manufacturing of a large reservoir of cultural imaginaries. (Mbembe 2019, 79)

Alexandre Baril (2023) observes a similar pattern of differential treatments offered to people according to, as Mbembe terms, the “cultural imaginaries” (Mbembe 2019, 79) of which they belong. A societal “natural attitude” (Ahmed 2006, 549) is evidently reflected in Baril’s description of “undesirable subjects” (Baril 2023, 3) whose *cultural imaginary* is evidently governed with different rules, different perceptions, of what it means to be human (Goodley 2020; Titchkosky et al. 2022). Baril explains:

> While some undesirable subjects—namely, visibly disabled/sick/ill/old people—are allowed (and sometimes even encouraged) to die in many countries, such as in the Canadian context in which I live, suicidal people perceived as 'salvageable' are forced to stay alive to become productive again in this neoliberal and capitalist world. (Baril 2023, 3-4)[11]

How might we interpret this medical dance between "cultural imaginaries" as a learning opportunity? As "cultural imaginaries" are the spaces in which we sort humans—spaces in which "different categories" with different rules appear to apply to different people (Mbembe 2019, 79), perhaps this dance offers a way to better understand the consequences of such a categorization process in relation to how we interpret life and death as "different categories" with "different goals" for different people (Mbembe 2019, 79).

Baril discusses their lived experience in obtaining a Do Not Resuscitate (DNR)[12] certificate—a process requiring a medical practitioner's authorization. Baril narrates their intimate relationship with suicidal ideation, revealing societal perceptions of disability,[13]

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[11] Similarly, interpretations of Baril's (2017) discourses on suicide are raised in Procknow's (2024) investigation into psychiatric euthanasia and assisted suicide (pEAS) and considers the ways in which "MAID creates two classes of suicidal subjects: one targeted to die and the other forced to live" (Procknow 2024, 57).

[12] Miceli (2016) tells us: "A DNR [Do Not Resuscitate] order calls for the withholding of life-sustaining, resuscitative treatment in the event of cardiac or respiratory arrest" (Miceli 2016, 111). Cleveland Clinic (2025) tells us: "Deciding to have a DNR order can empower you by making you feel more in control of your own life" (Cleveland Clinic 2025, If CPR saves lives, why would anyone want a DNR order? section, para. 1).

[13] Diane Coleman (2010) highlights the inequality experienced by disabled people when it comes to responding to the appearance of suicide wherein nondisabled persons are offered suicide prevention measures. However, disabled persons are offered suicide assistance. See the following reference for further discussion: Coleman, D. (2010). Assisted Suicide Laws Create Discriminatory Double Standard

assisted suicide, and "[t]he logic of suicide prevention itself, aiming to cure the suicidal self" wherein participants find themselves engaged in processes orientated towards "producing able-bodiedness"[14] (Baril 2023, 4). Baril tells us:

> Obtaining the official DNR order was complicated […] My doctor explained that he might have actually suggested I complete a form to get a DNR order had I been 'old' or 'severely disabled/sick/ill.' However, since I was relatively young at the time of the request (under forty), relatively healthy, and 'only' living with chronic pain, an invisible disability often dismissed by the medical-industrial complex, I seemed to have no 'good' reasons to justify a DNR order. (Baril 2023, 3)

Baril explains, "I had to prove my sanity and my rationality. I had to expunge any crazy bits of madness while talking to them […] because being honest has huge costs" (Baril 2023, 4). In fact, Baril reveals that they felt it was necessary to deceive their doctor—to mask their suicidal ideation—a method towards achieving their desired *cultural imaginary* assignment (Mbembe 2003; 2019). Baril explains that suicidal people are,

> subjugated to a vast array of discriminations and forms of violence. Suicidal people are routinely refused job opportunities based on their suicidal history; are denied life and health insurance; are labeled as incompetent parents and lose custody of their children; are deceived by suicide prevention hotlines that trace their calls and force nonconsensual interventions upon them; are handcuffed, arrested, and mistreated by the police (a violence deeply exacerbated when suicidal people are racialized, Indigenous, poor, neurodivergent, or Mad); and are forcibly hospitalized, physically restrained, and drugged against their will. Aware of these consequences of being honest about my suicidality, I, like many other

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for Who Gets Suicide Prevention and Who Gets Suicide Assistance: Not Dead Yet Responds to Autonomy, Inc. *Disability and Health Journal, 3*(1), 39–50. https://doi.org/10.1016/j.dhjo.2009.09.004

[14] Queer theorist Jasbir K. Puar's use of the term "capacitation" (Puar 2017, xviii) is recognized by Baril (2023) as one form of response to the appearance of "salvageable" subjects. "Contrary to people who are visibly disabled/sick/ill/old, who are 'abject' subjects according to ableist and ageist norms and structures, I am considered redeemable, salvageable, a subject targeted by forms of rehabilitation" (Baril 2023, 3).

> suicidal people, have concealed my suicidal ideation from therapists, psychologists, and health care professionals to avoid these sanctioned forms of criminalization, stigmatization, pathologization, incarceration, and discrimination. (Baril 2023, 4)

Baril's discussion overlaps with my work as I investigate the meaning assigned to disability as one cultural imaginary that is perhaps ruled by a different set of laws, governed under a different set of rights and a different set of goals (Mbembe 2003; 2019). Baril's investigation of the "sanctioned forms of criminalization, stigmatization, pathologization, incarceration, and discrimination" (Baril 2023, 4) begin to reveal the consequences of being sorted into undesirable categories, all which Baril details their hyperawareness as a person who identifies as suicidal.

Understanding the Narratives of Suicide and Disability

Understanding the narratives told by disabled, Mad, chronically/terminally ill, and suicidal persons is crucial to understanding how death is socially organized in contemporary Western society. Death becomes increasingly tempting[15] for those who are systemically subjugated to, as Mbembe describes:

> the various ways in which, in our contemporary world, weapons are deployed in the interest of maximally destroying persons and creating *death-worlds,* that is, new and unique forms of social existence in which vast populations are subjected to living conditions that confer upon them the status of the *living dead* [...] today's form of necropower blurs the lines between resistance and suicide, sacrifice and redemption, martyrdom and freedom. (Mbembe 2019, 92)

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[15] Achille Mbembe notes that choosing "death is precisely that from and over which I have power. But it is also the space where freedom and negation operate" (2019, 91-92).

It is no stretch of the imagination to consider the creative ways in which dominant storytellers (e.g. medicine, education, bureaucracy [Titchkosky et al. 2022]) might warp—even weaponize—the appearance of death as a seductive escape for those who, as Simon Spichak posits in their article titled *Canadians with disabilities remain locked in "legislated poverty," and many want to die* (2024). Spichak tells us:

> Increasingly, Canadians with disabilities are asking for medically assisted death, facing overwhelming poverty, rapidly rising housing costs, and many are unable to get the health and medical supports they need to live a life with dignity and without pain. (Spichak 2024, para. 2)

Suicidal people are "subjugated to a vast array of discriminations and forms of violence" and "incarceration" (Baril 2023, 4). MAID provides a new set of pathways for suicidal persons (whether direct or indirect; a symptom of existing mental health conditions, or a lack of alternative *liveable* options made accessible for marginalized populations) (Mbembe 2019 [2003]; Mills 2020; Baril 2023; Procknow 2024).

A Personal Position: Autonomy, Worry, Fear, and Hope

It is crucial to emphasize the importance of agency and autonomy. Every human should have the right to exercise autonomy—to govern the ways in which one lives and the ways in which one dies. My concern rests within the tensions that complicate our decision-making processes, more specifically, I worry about the ways in which we arrive at our decisions to achieve death. I worry about the rationales that justify and guide our decisions toward assisted suicide. My position is not one that interprets death by MAID as *the wrong way* to achieve death. My position is one of hope. My hope is that those who achieve death by

MAID also achieve peace. My fear and my worry stem from the ways in which medical assistance in dying has been understood as the only viable option left, for example, for those who have already described their way of life as one that is no longer *liveable*, durable, tolerable (Procknow 2024). In addition, I worry too about the power of societal perception that depict disability and chronic illness as burdensome bodies that ought to consider death as a reasonable solution to their *problematic* existence (Mitchell 2002, 15).

Article: *Why Do Patients Agree to a "Do Not Resuscitate" or "Full Code" Order? Perspectives of Medical Inpatients* (Downar et al. 2011)

A study conducted in Toronto, Canada investigates the reasons why patients choose to pursue "FC [Full Code] or DNR [Do Not Resuscitate]" orders (Downar et al. 2011, 584). Downar et al. tells us that "patients who were admitted to the medical wards of three academic tertiary care hospitals in Toronto, Canada (Toronto General Hospital, Toronto Western Hospital, and Mount Sinai Hospital)" (Downar et al. 2011, 583) expressed the following "[r]elational factors" (Downar et al. 2011, 584) in response to why they chose DNR:

> Relational factors were divided into familial and societal considerations. DNR patients expressed a desire to avoid resuscitation in order to lessen the emotional burden on family members [...] [o]thers were concerned about the financial costs to society as a whole. (Downar et al. 2011, 584)

Goodley underscores the need for "[u]npacking the ideology of ableism" (Goodley 2017, 57) through a critical lens in his chapter titled *Difference: Disability, Gender, Race, Sexuality and Social Class*.[16] Goodley tells us,

> The critical study of ableism [...] would question the bedrocks upon which some human beings are recognised as having citizenship, valued lives and honoured bodies. Unpacking the ideology of ableism invites us to contest the ways in which only particular formations of humanity are deemed worthy of fighting for. (Goodley 2017, 57)

My concern fixates upon the ways in which we arrive at these decisions, particularly within contemporary Western society. Western conceptions of a desirable life, or a "life worth living", is not likely to include the appearance of disability (Reynolds 2022, 4). I consider the accounts of Toronto-based assisted suicide cases reported in the news media that discuss disability as a reasonable rationalization for seeking assisted suicide (Stefan 2016). Such an explanation reinforces the normative perceptions that recognize disability as an acceptable reason to justify assisted suicide (Baril 2023).

The Pursuit of a Healthist Society with Supposed Good Intentions

China Mills' chapter titled *Strengthening Borders and Toughening Up on Welfare: Deaths by Suicide in the UK's Hostile Environment*[17] explores "some of the ways that welfare and

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[16] See Dan Goodley's (2017) book, *Disability Studies: An Interdisciplinary Introduction,* for further rich discourse in critical disability studies.

[17] For further discussion into the politics of suicide, see: Button, M. E., & Marsh, I. (Eds.). (2020). *Suicide and Social Justice: New Perspectives on the Politics of Suicide and Suicide Prevention*. Routledge.

immigration detention ‘practices’[18] kill people” and argues that the UK’s normative “lethal”[19] practices of “hierarchisation” are “inseparable” from suicide promotion (Mills 2020, 71). Mills argues that “hostile environments are crafted and designed with intention” noting “that even if policy makers don’t intend for suicide in response to these policies, the system is designed to produce certain conditions of hostility and these conditions invite suicidality” and “are affective – they make people *feel* particular ways (such as ashamed, exhausted and hopeless)” (Mills 2020, 71). Mills concludes that “the underlying logic of these systems”—including “welfare, disability and distress” practices— “create conditions that devalue certain lives, and kill people, partly through inciting them to kill themselves” (Mills 2020, 83).

“Basically my contention” explains Irving K. Zola “is that the increasing use of illness as a lever in the understanding of social problems represents no dramatic shift from a moral view to a neutral one but merely to an alternative strategy” (Zola 1977, 64-65). Similar to Mills’ (2020) work, Zola too recognizes the significance of *intentions,* as explored in their chapter *Healthism and Disabling Medicalization* (1977). Zola considers the ways in which society appears to perceive medicine as a method for *solving problems*:

> The problem being scrutinized and the person being changed is no less immoral for all the medical rhetoric. It or he is still a ‘problem’, though the rhetoric may convince us that he and not the society is responsible, and he not the society should be changed. Even the moral imperatives remain, in the idea that if such a problem-person can be medically-treated-changed, it-he *should* be. (Zola 1977, 65)

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[18] Stevenson (2012; as cited in Mills 2020). Reference: Stevenson, L. (2012). The psychic life of biopolitics: Survival, cooperation, and Inuit community. *American Ethnologist, 39*(3), 592–613. http://www.jstor.org/stable/23250787

[19] Povinelli (2011; as cited in Mills 2020). Reference: Povinelli, E. (2011). *Economies of Abandonment*. Duke University Press.

In understanding the "use of illness as a lever" and "alternative strategy" for "handling [...] social problems" (Zola 1977, 65), Zola suggests "that medicine is becoming a major institution[20] of social control" (1977, 41) wherein "biological and supposed health differences have been used to exclude [certain individuals] from many aspects of life" (Zola 1977, 65). Zola concludes,

> But here the danger is greater for not only is the process masked as a technical, scientific objective one but one done for our own good. In short, the road to a healthist society may well be paved with supposedly good intentions. (Zola 1977, 67)

The concept of intentional disabling practices toward "a healthist society" is perhaps made more disturbing through Zola's critical lens of social construction suggesting that such practices are "paved with supposedly good intentions" (Zola 1977, 67).

Carol J. Gill's (1999) chapter titled *The False Autonomy of Forced Choice: Rationalizing Suicide for Persons with Disabilities* investigates the ways in which one might make sense of suicide for certain individuals with, as Zola describes, "supposed health differences" (Zola 1977, 65). This sense-making process appears to be structural through

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[20] Similarly, Dan Goodley identifies medicine as *hegemonic* and tells us: "The medical model becomes hegemonic—it becomes a ruling ideological position and totalising discourse—encouraging the disabled object to be framed in terms of assisted suicide, euthanasia and antenatal termination" (Goodley 2017, 8). It is important to note Goodley's follow up comment: "This is not to suggest that medicine has not helped people. Medicine, rehabilitation and therapy have given life. But problems occur when we move from medicine to the medicalisation of life" (Goodley 2017, 8). We must also consider how it is that we understand the dynamic relations existing in-between "medical intervention and a defined patient role" that perhaps "offers a label [namely, disability and illness] as explanation" (Goodley 2017, 7). In this way, explanation operates as reason, sense-making, and rational pattern of logic that perhaps work toward dismissing the deaths of disabled and chronically ill persons—given the general dominant interpretations of one's medically assigned labels to be "'good' [enough] reasons to justify" death (Baril 2023, 3).

and through. This structure of logic (Mills, 2020) is perhaps, “done under the guise of autonomy rights discourses and democratizing access to death” (Procknow 2024, 74).

Greg Procknow’s article, *The Necropolitics of Psychiatric Euthanasia and Assisted Suicide (pEAS)*, “critique[s] the State granting medical assistance in dying (MAiD) access to those whose sole underlying medical condition is a mental disorder” (Procknow 2024, 50). Procknow[21] explains: “As biopower seeks to maximize life, I argue that MAiD, as a necropolitical weapon, minimizes (and cheapens) it by dispensing death” (Procknow 2024, 56). Procknow’s work is critical and timely—poignantly emphasizing the need for “critical analysis of psychiatric euthanasia and assisted suicide (pEAS) in the Canadian context given that our sunset clause expires soon, after which Canada will become the most MAiD-permissive jurisdiction the world over” (Procknow 2024, 51-52).

The existing research put forth by the scholars in this literature review recognize the systemic patterns of privileging some lives over others. Zola (1977), Gill (1999), Goodley (2017; 2020), Mbembe (2019 [2003]), Mills (2020), Baril (2023), and Procknow (2024) prompt us to consider how we interpret the social values laced throughout the dominant narratives we encounter as disabled people—as those labeled with a marker of “supposed health differences” (Zola 1977, 65). If the euthanizing process of achieving death is indeed “grounded in its disposal of difference” for the lives “deemed unviable or as non-durable”

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[21] Procknow expands upon the role of necropower in relation to MAID in the Canadian context. Procknow tells us: as “[t]he State’s designs include expanding necropower by widening the psychiatric turf to proliferate pain and waylay more mad minds into demanding its euthanizing services” (Procknow 2024, 74), Procknow “anticipate[s] the conditions for granting [euthanizing services] will be enumerated in the DSM, along with procedures for processing hastened death requests of patients” (2024, 74).

(Procknow 2024, 74), we must consider the boundaries of difference that perhaps indicate the achievement of a satisfactory "healthist society" (Zola 1977, 67).

The consequences of holding back our critical questions reach beyond the loss of life. We risk the collective shift in perception that becomes content with, as Dan Goodley describes as: "this potential for the human category to divide and rule—to let in some and force out others" (Goodley 2020, 23).[22] To "divide and rule" is, perhaps, a path of reaffirming that some humans matter more than others (Goodley 2020, 23).

Achille Mbembe explains, "sovereignty means the capacity to define who matters and who does not, who is *disposable* and who is not" (Mbembe 2019 [2003], 80 [27])—a sentiment that "is itself underpinned by the idea that the state [i.e., the one in power] has a divine right to exist, a narrative that competes with another for the same sacred space" (Mbembe 2019, 80). And yet, we tend not to wonder about the ways in which the question of disposability of the one(s) in power is determined, defined, even contested.

I conclude this literature review by drawing our attention to Goodley's (2020) and Mbembe's (2019 [2003]) work, through which we might begin to understand the methods of perceiving disability and interpreting the human body as a way to make sense of who we expect to show up in the context of death, suicide (non-assisted), and assisted suicide (MAID). Different values and different meanings are assigned to different bodies and different "classification[s] of people" (Mbembe 2019 [2003], 79 [26]). It is paramount that we continue to question medicine's practices and consider that they may not be paved

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[22] See Dan Goodley's book, *Disability and Other Human Questions*, for further discussion about "explor[ing] the ways in which normal, everyday and typical understandings of the human being are, in reality, incredibly exclusionary: including some and omitting others" (Goodley 2020, 23).

with good intentions (Zola 1977), but rather, as Mills suggests, contribute toward a structure of logic that operates to "devalue certain lives, and kill people, partly through inciting them to kill themselves" (Mills 2020, 83).

Now Toronto Article: "Op-ed: ODSP rates are killing people in Ontario" (Glover 2022)

This discussion continues towards news media narratives wherein disability advocates contribute towards situating the lived experiences of two disabled women of Toronto in relation to their choice to pursue MAID. This narrative account provides insight into the social supports made available to disabled people, and the quality of life that such supports might afford (as situated in Ontario, Canada). On June 30th, 2022, Chris Glover (MPP [NDP] for Spadina-Fort York) writes in *Now Toronto*:

> There are people in Ontario with disabilities who are choosing to die because they cannot live on the $1,169 per month provided by ODSP [Ontario Disability Support Program]. CTV reports that Denise[23] [of Toronto] – who is 31 years old, uses a wheelchair and has multiple chemical sensitivities – has 'applied for MAiD (medical assistance in death) essentially…because of abject poverty.'[24] She cannot afford a wheelchair-accessible apartment with cleaner air that is safe for her illness.
>
> In a similar case, Sophia[25] [of Toronto], another Ontarian with a disability, opted for a medically assisted death in February because she also could not

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[23] Please note, Denise is a pseudonym used to protect the identity of the individual. (Favaro 2022b)

[24] Favaro (2022b, para. 7; as cited in Glover 2022, para. 1). See the following reference for the full interview conducted with Denise, written by Avis Favaro (2022b) from *CTV News*: Favaro, A. (2022b, April 30). *Woman with disabilities nears medically assisted death after futile bid for affordable housing.* CTV News. https://www.ctvnews.ca/health/article/woman-with-disabilities-nears-medically-assisted-death-after-futile-bid-for-affordable-housing/

[25] Please note, Sophia is a pseudonym used to protect the identity of the individual. (Favaro 2022a)

> find housing that could accommodate her disability.[26] These are not the only two cases. London Ontario ICU physician Dr. Scott Anderson reports seeing more patients asking for MAiD because they cannot afford the services they need to accommodate their disabilities. (Glover 2022, paras. 1-2)

This short account of death belongs in the interpretive framework of MAID and is an example of social action towards suicide prevention through narrative methods. Glover (2022) reports the lived experiences of two disabled women who pursued (and achieved) death by MAID because they were unable to acquire safe, accessible, affordable housing in Toronto, given their limited income (social assistance) as provided by ODSP (Ontario Disability Support Program). Both women are categorized as *Track 2* cases. Track 2 "[r]efers to a request for MAID made by a person who meets the eligibility requirement set out in the *Criminal Code* and whose natural death is not 'reasonably foreseeable'" (Health Canada 2024, 11). Track 1 "[r]efers to a request for MAID made by a person who meets the eligibility requirements set out in the *Criminal Code* and whose natural death is 'reasonably foreseeable'" (Health Canada 2024, 11).

Glover explains that "ODSP rates kill because they do not provide Ontarians with disabilities enough income to live" (Glover 2022, para. 4). This raises the question: How are disabled people (living in Toronto or otherwise) meant to make a choice that blurs the line between what it means to live in abject poverty, and what it means to make a conscious act towards achieving accessible death?

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[26] On April 13th, 2022, Avis Favaro from *CTV News* writes about Sophia [of Toronto, Ontario] in their article: *Woman with chemical sensitivities chose medically-assisted death after failed bid to get better housing*. "She [Sophia] died [on February 22nd, 2022] after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto" (Favaro 2022a, para. 4). Full article available at the following: https://www.ctvnews.ca/health/article/woman-with-chemical-sensitivities-chose-medically-assisted-death-after-failed-bid-to-get-better-housing/

Sovereignty, Agency, Power, and Control

"In this case, sovereignty means the capacity to define who matters and who does not, who is *disposable* and who is not" (Mbembe 2019 [2003], 80 [27]).

Achille Mbembe puts forward the notion of *Necropolitics* to account for "contemporary forms of subjugating life to the power of death" (Mbembe 2019, 92). Mbembe tells us, "one is free to live one's own life only because one is free to die one's own death" (2019 [2003], 90 [38]). I wonder what it means to be free. I wonder how a person exercises the act (or the *doing*) of freedom. I wonder what such an activity, or way of being, looks like. How do we know that our actions represent an expression of our own free will? Is the notion of freedom akin to the notion of agency—or is freedom simply an abstract construct that describes one's capacity to perform agency… that is, if one chooses to do so?

Mbembe describes human death as a conscious, voluntary act: "By transforming nature, the human being creates a world […] In the Hegelian paradigm, human death is essentially voluntary. It is the result of the subject's consciously assuming risks" (Mbembe 2019, 68). In this way, death is socially accomplished through a negotiation with agency, freedom, power, and control. Perhaps, as Mbembe suggests, "one is free to live one's own life only because one is free to die one's own death" (Mbembe 2019 [2003], 90 [38]).

The "mirage"[27] (Stiker 1999, 134) of negotiating power and control over one's way of life (and way of death) is accomplished by narrating agency as an attainable practice. MAID becomes an accessible, "progressive and humane" (Frazee 2024, 1) approach towards agency—a pathway towards attaining some assemblance of freedom. To claim power over one's own fate may be understood as a way to exercise a way of being free…[28]

Conclusion

I will now return to my guiding questions: If there is nothing natural about death, how is death socially organized? How is death limited and how is death made possible, and achieved? How ought we begin to inquire about the *natural*… is it a question of natural death—natural life? Who defines what is natural? Is natural understood as a feature that may describe a way of *being*… or is natural only significant in certain ways for certain people? I wonder if the pursuit of MAID and the achievement of death might be understood

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[27] Henri-Jacques Stiker's chapter titled: The Birth of Rehabilitation, in *A History of Disability* notes: "the mirage is produced" through designating credibility "in order to be made [to] disappear" (Stiker 1999, 134). See the following passage for further discussion: "Paradoxically, they [disabled people] are designated [with a status] in order to be made [to] disappear, they are spoken in order to be silenced. This is a contradiction, of course, but has its basis in the play between being and seeming in our society. The more their social elimination becomes possible, the more their medical, psychological, even sociological existence is affirmed. This is how the mirage is produced: […] credibility being sought for the claim that the problem is really being solved." (Stiker 1999, 134)

[28] *A Way of Being Free* is a book written by Nigerian storyteller Ben Okri (1997). Okri tells us that "we live by stories, we also live in them. One way or another we are living the stories planted in us early or along the way, or we are also living the stories we planted—knowingly or unknowingly—in ourselves. We live stories that either give our lives meaning or negate it with meaninglessness. If we change the stories we live by, quite possibly we change our lives" (Okri 1997, 46). Okri's words prompt my inquiry into *being free.* Okri's words remind me that we make meaning through interpretation, and we seek to make sense of the stories we tell ourselves and retell the stories that we have been told. The ways in which we exercise agency might speak to the ways in which we understand the stories that we have lived, and the stories that we have yet to live. Our understandings may situate us within our choices and often seek to explain to ourselves (and to others) how it is that we come to (i) interpret and make meaning of our lives, (ii) make meaningful choices.

as an unnatural path for all “whose natural death is not ‘reasonably foreseeable’” (Health Canada 2024, 11) (i.e., the portion of the Canadian population measured and deemed healthy by Health Canada’s self-proclaimed standards), or if the pursuit of MAID is merely a sensible path towards the achievement of death for those who are not deemed healthy—as measured by the standards set by Health Canada.

The question of natural death, natural life, and the “natural attitude” (Ahmed 2006, 549), appear to bear definitions, implications, and vastly different narratives that limit and restrict perception in different, yet somehow similar ways. This exploration awakens the need to pursue interpretive methods as a way to reconstruct and inquire about our meaning-making processes. Interpretive methods awaken our need to question the narratives that reflect a “natural attitude” (Ahmed 2006, 549) and contain cultural values, beliefs, assumptions, and priorities—all of which orient our perceptions of the value and the meaning we assign to human life. We must engage with a *phenomenology of hesitation* (Al-Saji 2014) when encountering dominant narratives that “define who matters and who does not, who is *disposable* and who is not” (Mbembe 2019 [2003], 80 [27]). Similarly, we might add to this line of inquiry toward defining *who* is natural and who is not—or rather, *what* is natural and what is not.

We must ask ourselves if our patterns of thought truly reflect our own values, beliefs, and decisions, or if our thought patterns simply mirror a dominant discourse that directs our daily patterns. As Glover states: “There are people in Ontario with disabilities who are choosing to die” (Glover 2022, para. 1). These people are gone. Denise and Sophia are gone. And I wonder… how did Denise and Sophia come to make their decisions? What hope is there for the future Denises and Sophias who find themselves unable to obtain safe, accessible, affordable housing in Toronto? I must ask myself, if I were to make a decision, such as Denise and Sophia had in 2022, would my decision be motivated by the intoxicating pull toward a way of being free? Would my decision reflect a conscious act of assuming risks… a decision constructed, as Mbembe suggests: “By transforming nature, the human being creates a world […] In the Hegelian paradigm, human death is essentially voluntary. It is the result of the subject’s consciously assuming risks” (Mbembe 2019, 68). As a disabled woman also living in Toronto, Ontario… would a decision to choose MAID—a conscious, intentional action towards the achievement of death—demonstrate my capacity for exercising agency? Is this agency synonymous with the choice to take control of my own power in which I might decide my own fate? Or is this merely a *mirage*… a method to reorient my perception, as crafted by Health Canada, toward that of responsibility and the greater good?

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