
Unmasking Intimacies of Death and Dying

SK Sabada

Abstract

This article was written during the early days of quarantine (circa Spring 2020) as a direct response to the concerns I and other disability justice advocates, and I began to feel around the treatment of disabled people amidst the COVID-19 pandemic. Chief among these concerns was the killing and letting die of disabled folx, as well as other "expendable" persons, such as frontline workers. Grounded in a radical approach to disability justice, below I analyze the constructions of death, dying, and personhood during the start of the global pandemic through the lens of "bare life" and the "state of exception". Drawing on these concepts, I examine the Canadian state's response to sickness as an invocation of catastrophe politics, something, which I argue, has led to an irrevocable change in how the deaths of marginalized populations, especially disabled folx, may be justified as inevitable, despite being completely preventable. These attitudes, which allow us to accept death for some and not for others, are another form of normalizing the culling down of life through state-sanctioned control. I thus conclude that COVID-19 has proven to be a state exercise in violence against "expendable" populations.

Keywords

bare life; state of exception; catastrophic politics; disability justice

A conversation in unmasking

When I am in class, at work, or generally near someone who is not a part of my immediate family or circle, I bite my tongue to suppress the many compulsions that I have, and that I know the non-disabled, neurotypical person who is (usually) nearby, does not. I ball my hands into fists to stop them from reaching toward the spaces I ought not to exist in; to stop myself from letting them shake and to try and release the energy vibrating throughout my body. Engaging in such behavioural modification in response to self-surveillance is not a new or ground-breaking phenomenon; indeed, it is so well-known within neurodivergent communities that we call the practice “masking”. Masking functions similar to other social-survival strategies, such as “code-switching” and “passing” among non-white and trans communities, which are comparably aimed at navigating dominant culture in space and time. Further, the neurodivergent mask also functions similar to its material counterpart, the facemask: it may hide or reveal something about the wearer, and how it “looks” may change over time, based on affect and depending on location. However, unlike literal masks, the metaphorical-embodied masks of neurodivergent people operate in relative performativity. For many of us, such masking is critical to our survival, and we have been performing it for so long that we may be unable to stop or have long since forgotten what it means to stop. For some, unmasking may not be possible at all.

As an autistic person who verbally communicates, I rarely make the conscious decision to mask. It is something I do to protect myself in regular life, whereby I have long learned to prioritize my safety over my desire to exist unrestrained by ableist conventions of conduct. However, in the wake of COVID-19 (hereafter, COVID) forcing everyone into self-isolation (or at least, in Ontario, where I currently reside), I have had to cope with the trauma that this highly contagious virus has actively produced, which, in turn, has allowed me to begin to unmask. Within this viscerally violent socio-health climate, I have permitted myself

permission to deal with the more sordid experiences of being mad and disabled during a global health crisis that takes my apparent sub-or-non-humanity as a given; ranging from stimming to performing rituals to insomnia, all of which has been triggered by the increased discussion of death within the media.

The ironic thing about death is that our culture, particularly within the context of North America, is permeated by a morbid fascination with death while simultaneously remaining incredibly death shy. Even more so, this fascination with death takes careful consideration of the deaths of marginalized people, namely Black and Indigenous people, poor people of colour, migrant workers, sex workers, trans folk, and disabled people. It is no secret that Indigenous, Black, and disabled lives have especially been made and remain precarious within our white settler ableist society (Weheliye, 2014; Piepzna-Samarasinha, 2018). From the colonization of Turtle Island to the transatlantic slave trade and the institutionalization, social sterilization, and mass euthanization of disabled people that led up to and persisted throughout the second world war, we have known what it means to lead conditional lives (Grue, 2010, p. 37).

For as much as western popular culture derides and sensationalizes death, it cares very little for it, particularly when it happens to vulnerable groups that have been discursively constructed as “the undesirable” through hegemonic notions of normalcy and the compulsory ableism, sanism, and racism therein. As specifically regards compulsory ableism, such hegemony is achieved through the naturalization of able-bodiedness as the only acceptable way of being (Campbell, 2008), which then works in tandem with other normalizing oppressions, like whiteness and sanism, to discursively regulate embodiments that counter it.

In the wake of my unmasking, I have had to reckon with these truths more than ever before and, more specifically, their role in my care networks with other marginalized and disabled people. Although I have always been aware of the precarity of our lives, the fact of said precarity has

shifted its position from my peripherals to the forefront of my conversations with others. No longer am I finding myself trying to assess and meet the needs of the people in my care network who also experience disability, but I also need to focus more clearly on my own, ever-increasingly hard to meet, needs – and I am not the only one. When many of our lives are under duress, meeting each other's access needs becomes more and more difficult. For instance, how can we begin to consider the best way to support a friend as they try to get medical care for a flare-up when even meeting with a doctor is nearing impossible?

It is in the roots of critical disability studies and disability justice activism that I begin to find answers to questions such as this. These perspectives make clear the necessity in examining the implications of having a body-mind orientation that is neither desired by nor protected from the state's violence and what this then means within our postCOVID worlding. Accessibility cannot be parsed out from its core motivation: to give disabled people the access we require to live in the world; to always secure said assistance, whether be it through law or technology, design, or education; to be able to live—actions that often indicate an individual's movement away from precarity and, by extension, from death. It is for this reason that disabled people and those who support us (namely migrant and non-white care workers) have no choice but to push back against the dominant discourses that are emerging during this pandemic regarding the “scarcity” of medical resources and the ethics of deservedness.

That this is the case has become increasingly more evident as the world has become both more medical and more digital. For example, folx who rely on ventilators (beyond COVID), may find themselves making plans to move, despite stay at home mandates, in the event that they need to access hospitals in the United States because they are at risk of having their ventilators taken from them.^{1,2} Similarly, older folx who live in care

homes may also feel a heightened sense of isolation as they are cut off from the outside world because the risk of contracting the virus is so high. These people—alive by all accounts—are taking on the role of living ghosts, forced to cheat unnatural deaths by violent logics, of total and unflinching supremacies based on the dehumanization of disabled people and the elderly.

Taking these and the other deathly realities of COVID life as my point of departure, I press the importance of acknowledging that there is no neutral position regarding death because death, just as life, is never a neutral state of existing. This pandemic has provided ample opportunity for nation-states and popular culture to reaffirm systems of oppression aimed at controlling and limiting access to support systems for marginalized groups most affected by the crisis. As someone whose body-mind orientation could easily render them disposable through the logic of ableism and eugenics, I have myself become somewhat of a living ghost. Yet, at the same time, as a *white* disabled person, I too am complicit in the harms experienced by non-white folx, who are also at-risk, largely due to the working conditions mobilized under COVID. Even if I do not directly rely on care workers or other essential workers that provide access to things, my whiteness renders me complicit in our current climate of racial violence, as this crisis is being sustained by the white supremacist, colonial, and capitalistic domination of non-white workers.

The palate of the Canadian government, which functions primarily through its exploitation of Black, Brown, Indigenous, and Asian workers, can do so because it forces marginalized people to believe that our survival depends on the state. It is for this same reason that government officials have framed its exploitation of non-white workers on the COVID frontlines as “essential”, while simultaneously treating them without dignity. By framing the pandemic and this section of the labour force in this way, those who rely on the

¹ New York State Ventilator Allocation Guidelines 2015, p. 42.

² Guidance for the Ethical Allocation of Scarce Resources

during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee, 2016.

medical institution (i.e., those most at risk of contracting the virus) experience subjugation through the “ethics” of deservedness in a crisis that the state frames through a scarcity of resources. This then fuels disabled people, who require access to food services and healthcare, to exploit and expose racialized and poor essential workers to avoid possible contraction of the deadly virus.

In turn, disabled people and non-white workers are concertedly implicated in and targeted by the death logics of COVID: The only way for disabled folx to survive is to exploit largely racialized and Indigenous workers and to put both them and ourselves at risk. Similarly, frontline workers in the medical world are called upon to fight COVID without proper protection or resources, rendering them at risk physically and mentally, while also acting on behalf of state interests that live and let die according to ableist, ageist, and racist ideologies. Further, despite the considerable differences in power between medical frontliners and disabled patients, both outcomes are okay by the Canadian state because, even if either disabled people or non-white workers contract the virus and die, our lives held little to no (real) weight in the first place.

It is within this conversation of dual precarity that my sense of unmasking finds its grounds. Amidst this pandemic, one which feels increasingly more digital due to quarantine and self-isolation protocols, I am discovering affective shifts in our culture related to the intimacies of death and dying. I am increasingly concerned about these intimacies because of the shift in the way we not only provide care (in both life and death) but also in how new this territory is concerning catastrophe politics and what that means for those navigating the blunt of local landscapes of death and dying. I especially fear the kinds of masks we will be expected to cultivate during times of grief and crisis; I fear how we may come to accept death as an isolating experience (even more so than it has already been featured in our death-shy culture). Specifically, I ask: “what new intimacies will emerge around COVID from our culture’s heightened fear of

subjugated bodies, living and dead, and how this shift might further erase the rights of, not only the actual dead but the ‘socially’ dead; the living ghosts, like me?”

Dying during a pandemic

Unmaking personhood through death

Before discussing how the rights of the literally or socially dead factor into catastrophe politics, it is important to recognize how death (that is, what it means to be a dead person) is currently articulated because the ways we recognize death have violent implications for disabled people. Given that death is often interpreted in multiple ways; from the literary and the fictional to the spiritual and religious; from the psychological, biomedical, and technological, to the social, political, and cultural, I wish to focus on the current biomedical tools that are used to define what it means to be dead. Specifically, I focus on the framework that the legal courts use to decide when and how lifesaving intervention may be used in the case of someone who is dying or is considered neurologically dead. The courts refer to criteria published in the *Canadian Medical Association Journal* guidelines, which constitute brain death as grounds for a death-diagnosis (Washington, 2018). The neurological definition identifies three kinds of brain death: whole-brain death, higher-brain death, and brain-stem death, with whole-brain death being the grounds for the official diagnosis of death. According to the Royal Canadian College of Physicians (2015), “whole-brain death implies that the entire brain, cortex and brain stem are involved with the complete and irreversible cessation of function of the brain at all levels”.

Interestingly, in the *McKitty v Hayani* (2019) decision, the preceding judge, Justice Lucille Shaw, concluded, based on these guidelines and, more specifically, the above working definition of brain-death, that a brain-dead individual does not qualify as a “person” who can assert their Charter rights. This ruling is especially significant for my analysis because it, and the case in which it was based, ended up having strong implications for the current death-scape of

the COVID-19 pandemic. Back in 2017, McKitty was found unconscious on a Brampton sidewalk where it was later discovered at a hospital that she had significant brain damage caused by hypoxia. Her physician, Dr. Hayani, placed McKitty on a ventilator and for a while, her brain stem continued to function, allowing her to breathe infrequently without the machine.

After suffering a second hypoxic event, however, McKitty was placed back on a ventilator, but this time was unable to regain the capacity to breathe independently. By September 2017, the doctor conducted the diagnostic tests required to determine whether McKitty met the criteria for whole-brain death, and they concluded that she did; however, McKitty's parents and substitute decision-makers sought an injunction that would prevent Dr. Hayani from removing life support from their daughter and this injunction was granted. McKitty's parents sought additional treatments and requested that her death certificate be rescinded. They argued that their daughter would not be dead until her heart stopped beating based on their religious beliefs. The constitutional question in the Superior Court challenge was in respect to the requirements used to determine death and, ultimately, the family's beliefs were overruled, and Ms. McKitty was taken off life support against her faith, as well as her parents' wishes.

The precedent this outcome set is troubling, not only regarding the injustices experienced by the McKitty family but in relation to how the outcome of the case provided a basis for the total reconfiguration of what it means to be a dead person. In the biomedical sense of death utilized by the court against the McKitty's, a person considered dead is not considered a person in the capacities that would allow them to be recognized as being human at all. Despite the justifications proposed by ethicists and physicians alike, in cases like McKitty's, the fact remains that, McKitty, and others like her, did not die on their terms. *Their lives were forcibly taken.* The qualifying factors for such death were not necessarily based on the notion that McKitty required *support* with breathing, but rather, that

her *perceived* lack of intellect – of thinking and of doing – denied her and her family the right to act in accordance with her beliefs (beliefs that she had held in her waking life). Even then, this factor was only deemed significant based on the perception of the care provider, not McKitty (re: a medical directive) or her kin.

In Justice Miller's statement on the definitions of total brain death within common law in *McKitty v. Hayani*, 2019, they wrote that:

The determination of legal death is not simply, or even primarily, a medical or biological question. The question of who the law recognizes as a human being – entitled to all of the benefits and protections of the law – cannot be answered by medical knowledge alone. Facts about the physiology of the brain-dead patient are needed to determine what obligations are owed to the brain-dead patient, but the enquiry is not ultimately technical or scientific: it is evaluative. Who the common law ought to regard as a human being – a bearer of legal rights – is inescapably a question of justice, informed but not ultimately determined by current medical practice, bioethics, moral philosophy, and other disciplines (para, 29).

Doctors have no right to unilaterally claim what constitutes death, yet they are afforded the absolute right to evaluate whether the state can take a life. Their evaluation is also often based, not on their medical expertise or hypocritical oath, but on outlying factors related to the cost of keeping the individual alive; the need to open up space for another critical patient; or on whether another patient's survival is considered more worthy of providing intervention – all of which were confirmed in an open letter from ARCH Disability Law to the Ontario Provincial government, citing how the current triaging program is designed to exclude disabled folk from receiving critical care based

on their respective disabilities³.

For physicians, ventilator users are being evaluated based on their net worth. Here, the chances of survival are circumstantial at best. Would a patient be taken off the machine at another hospital? Or under another doctor? What would have happened if they were given all treatments before their attending doctor decided to check whether or not they met the criteria for a death diagnosis? Of course, in acknowledging the extent to which such sensitive decisions have been left up to attending physicians to make, it should also be noted that blame for the inadequate treatment of disabled people does not solely fall on healthcare workers. These decisions would not have to be made at all, if the state provided enough adequate resources in the first place. Instead, the state puts healthcare workers in agonizing positions wherein the very lives that they are responsible for are subject to the whims of a genocidal social order that shows little in its capacity to understand the significance of providing care for, not only as many people as necessary, but in ways that are human and dignified.

The McKitty v. Hayani case best emphasizes the problem. This decision was made pre-pandemic and indicates that those who are afforded the recognition of being a human being are beholden to notions of functionality. When the recognition of human life is only understood through the lens of functionality, it puts both disabled and elderly folk who need care at risk. According to state regulations, if one is perceived to be low-functioning by attending healthcare workers, this can determine their access to life-saving and life-extending care. Take, for example, recent reports from the United Kingdom, wherein autistic adults and adults with learning disabilities were automatically given “do not resuscitate” notices should they require COVID-related care (Tapper, 2021, “Coronavirus: Autistic Support,” 2020).

Although this was widely condemned by the Care Quality Commission (Tapper, 2021), it should have never even happened. There was no adequate justification for applying blanket DNR notices to autistic people and people with learning disabilities beyond the fact that they were disabled, and subsequently considered “less functional”. In this and in many other postCOVID instances, disabled people are being constrained by pervasively ableist and capitalist understandings of disability that favour high-functionality, which, in turn, means that being disabled, being possibly “low-functioning”, can be taken as an indictment against one’s access to care.

Fast forward to the present, people who are critically ill with COVID, most of whom are the elderly, the disabled, the poor, the non-white, and migrant workers, exist on the same continuum of life and death that has long haunted our medical system. The sicker one is with the virus, the closer they are to death, and the less they are to be recognized as a person, just as the more marginalized one is, the more likely they will be infected with COVID. We are hearing and reading more stories of people dying (whether they are succumbing to the virus “naturally” or are being culled) at alarmingly progressive rates, specifically in long-term care homes and in migrant and non-white workplaces, and in more uncertain and terrifying conditions, no less.⁴⁵ Within this terrifying milieu, the careful intimacy between those dying and their support networks is being destroyed as the former is forced to die alone.

Further, while essential workers are crucial to the containment of the virus, they are being put in increasingly precarious positions. They are overworked to the point of exhaustion and are being ordered to make life and death decisions because the state did not prepare them with enough supplies to save lives and protect themselves. Hence, they too are being treated as

³ ARCH Disability Law. (2020, April 8). OPEN LETTER: Ontario’s COVID-19 Triage Protocol.

⁴ Alexiou, G. (2020). *Doctors Issuing Unlawful ‘Do Not Resuscitate’ Orders For Disabled COVID Patients*

‘Outrageous.’ Forbes.

⁵ Kirkey, S. (2021). *Ontario urged to suspend the need for consent before withdrawing life support when COVID crushes hospitals.* National Post.

non-human subjects as their labour becomes the ground that can be used to constitute their exploitation by the state. Relatedly, the rate of infection among marginalized folx, including racialized frontline workers, is astronomical; reports from the CDC and WHO were wrong in their initial claims that the only *real* at-risk groups are those who are chronically ill and elderly.⁶ Indeed, it is the chronically ill and elderly *without support* who are dying; it is the Brown Amazon courier who is getting sick, the *poor* disabled person in isolation struggling, and the Black and Indigenous communities whose bodies are plagued by centuries of systematic violence and neglect who have the “pre-existing conditions” necessary to succumb to the deadly virus.

It should come as no surprise that the pre-existing legal definitions of death have had horrible implications for the intimacies of death and dying in the wake of COVID. On the one hand, who gets to live (who deserves a ventilator and who does not) is steeped in ableist, ageist, capitalist, and racist state sanctioned definitions of life and death that do not serve everyone equally or equitably. However, on the other hand, the inadequacy of the pandemic management and treatment of those at-risk of COVID has put essential workers in a position where they (and by proxy, the rest of us) are forced to accept new intimacies that are primarily sustained through isolation, thereby leaving us with a totalizing form of grief that we are unequipped to handle.

Bare life in the catastrophe zone

In examining questions of death amid COVID, it is important to consider Giorgio Agamben’s concepts of “bare life” (1998) and “state of exception” (2005), especially regarding how they appear in Alexander G. Weheliye’s (2014)

seminal work in *Habeas Viscus*. Here, Weheliye mobilizes Black feminist theories of the human to question larger constructions of the human/man and, more specifically, how western categories of the human actively render certain groups non-or-not-quite-human to give other groups more power and control.⁷ In his explanation of Sylvia Wynter’s critical intervention into theories of western humanism, or “the genre of human as Man”, Weheliye acknowledges that the epistemic order of “the biological selectedness of man” also emerges from that which it categorically separates, including other non-white people, poor people, trans and queer people, and disabled people (p. 28).

This observation is important because it provides a way to understand the figure of *homo sacer* (sacred man) as it relates to bare life and a state of exception. Agamben (1998) uses the figure of *homo sacer* to describe a figure “who may be killed and yet not sacrificed, and whose essential function in modern politics we intend to assert” (p. 21). The life of the *homo sacer* is rendered bare by their isolation both from the state and others, ergo, bare life. Alternately, a state of exception refers to the process by which a sovereign “decides when the rule of law is suspended” (Downey, 2009, p. 111). When a state of exception becomes the rule, the boundaries between what is included and excluded (i.e., bare life) begin to blur. That blurring creates a zone of indistinction in which those within boundaries of life and death, are both subject and excluded from the larger projects of the state (Weheliye, 2014, p. 34).

Regarding the pandemic, the Canadian government must exercise a state of exception in reference to both patients and health workers as the site of the hospital transforms into a catastrophe zone. The catastrophe zone is best

⁶ In an update published by the English Office for National Statistics, research showed that 60% of those who died from COVID-19 were disabled (Ayoubkhani & Bosworth, 2021).

⁷ Weheliye’s (2014) work is grounded in a terrain of Black feminist studies committed to examining how anti-blackness and white supremacy are woven into the very core of western humanist frameworks. It would thus be

inappropriate to utilize his insights and general insights to conflate the dehumanization of white disabled folx with the abjection and subjugation of Black and other non-white groups. For this reason, I turn to his work not because all configurations of the non-or-sub-human should be treated as the same, but rather to explore how these experiences of non-human personhood circulate in relation to one another.

understood as a space in which the boundaries between bare life and "normal" life become blurred through the indistinctions caused by the space serving as a state of exception. The pandemic created an environment that defamiliarized the hospital grounds in such a way that all life that moves through it, moves through zones of catastrophe, and those lives, in turn, are affected to varying degrees of intensity. More specifically, the catastrophe zone becomes a limbo of sorts, in which patients and staff alike are never featured as living subjects, merely subjects who will or will not survive.

To exercise total control and containment in this death-laden climate, the state requires a suspension of the law (which we might read as the suspension of legally or even morally "correct" beliefs and decisions, creating a state of exception). The state of exception in this way, identifies that those within the catastrophe zone are prohibited from the kinds of life that exist outside of it (Agamben, 2005, p. 1). In turn, the presence of death among our postCOVID medical world becomes twofold, with both clinical death and social death at the forefront: a person who requires support to be sustained can already be made dead before they are, as those left working are given the authority to take life, while being denied the resources to save it. At the same time, medical workers are also forced to work longer hours without the adequate resources to protect themselves from contamination, and, subsequently, are disavowed of the kind of life they were once granted outside of the catastrophe zone.

Frontline healthcare workers thus embody a dual state of exception because, although they may be instruments of the sovereign state, they are also without state protection. In other words: "this 'state of exception' does not refer to an exclusion, but rather an abandonment that implies survival in a 'legal limbo' where 'life is held in suspension, neither inside nor outside the polis, neither fully alive nor dead'" (Lewis, quoted in Adams & Erevelles, 2017, p. 355). The labour of essential workers amidst COVID positions them within the frame of bare life because they are

essentially not yet in a state of dying but are always on the precipice of doing so. As pointed out by Goodley, Lawthom, and Runswick-Cole (2014), it is important to recognize the use of the state of exception as it relates to health workers in tandem with the idea of slow death: "a concept that refers to the physical wearing out of a population and the deterioration of people in that population, which is very nearly a defining condition of their experience and historical existence" (p. 981). For those doing frontline health labour in a state of exception, and who have essentially been abandoned to work until they can work no more, using slow death as a means of naming harm is critical when accounting for how these workers cope with and push against the toll of a mismanaged pandemic, thus highlighting the evolving scope of social death via COVID.

That said, despite sharing the experience of bare life, it would be problematic to argue that dying patients experience bare life in the same way as their care providers do. Although patients and staff each retain their identities as products and mechanisms of the state under COVID (as nobody is immune from its biopolitical power), the bare life experienced by patients is more visceral, more literal, than that of the staff. Patient lives are generally understood to be less important to the state because they are less commodifiable (as well as also less monied, less white, and generally less privileged). Even the lives—or, better yet, the *deaths*—of patients otherwise considered young and/or non-disabled (which is often conflated with healthiness) only matter in terms of the volume at which they are happening. For disabled and elderly (coded "unhealthy") populations, the loss is not even registered, as it is considered insignificant outside of the context of the value that they add to their respective communities. So, unlike health providers, who are pushed to the brink of bare life during COVID, the patients of this same crisis have long resided in or near the zone of social death that constitutes this ghostly social realm.

Nonetheless, bare life is a common attribute across medical worldings postCOVID. For as

much as care remains lucrative concerning care work as an industrial complex, the actual value attributed to care-workers and their patients alike, remains largely cultural, and our culture is hierarchical and inhumane. Thus, if anything, the deaths of medical frontline workers may be considered “more” tragic, but there is still no real political significance afforded to them. Similarly, while disabled and elderly populations were advised to self-isolate in the wake of COVID, there was still initial irritation from the invulnerable population (invulnerable here is a reference to those not identified as at-risk, i.e., largely the young and able-bodied, and implicitly monied) before it became clear the COVID-related deaths were wide-reaching.

The original dismissal of social distancing from invulnerable people highlighted the ablest underbelly of our culture: vulnerable people’s deaths were expected, even naturalized to an extent. Ever so casually, vulnerable groups were simply meant to die. Even in the case of the invulnerable who argued in support of social distancing to “protect” our fragile states, this further fed into the belief that we have a natural disposition towards death. Social distancing was articulated as a defensive position invulnerable people were supposed to do to protect us but realistically functioned as an offensive position backed by the government, who suggested they could control the volume of deaths, not including those who were already inclined to die.

In some sense, dying while old and disabled is likened to cheapening the full effect of dying while young and healthy. Similarly, dying while on the medical frontlines during a pandemic is likened to an unavoidable or necessary cost of life for the state as such. Hence, those who are disabled and/or work within the catastrophe zone become the *homo sacer* of the time of COVID precisely because they have been disavowed of their lives (both literally and politically). Keeping with the definition of *homo sacer* as “someone ‘who may be killed and yet not sacrificed’” (Reeve, 2009, p. 204), we can easily acknowledge disabled people and health workers as those who have been abandoned both by the state that triages

and mitigates care and through the corresponding death logics that decide what constitutes a life worth living.

The undergirding implication in the connections I have drawn here, specifically between disabled people and health care workers under COVID, is that catastrophe politics are the binding force between the two groups: although we have all entered into a state of bare life in the site of the catastrophe zone, i.e., the COVID-19 pandemic, disabled and elderly people are not killed or let to die, so much as they are *culled*. As soon as our bodies require more substantial support (i.e., ventilation), the act of dying (with the result being simply dead) transforms into dying, necessitating culling (to be killed). Ironically, the decision to use life-saving intervention is coded as an invitation addressed to health workers to partake in the act of killing. The decision to provide support exists in tandem with the exception (ultimately configured as necessity) to kill.

Other than COVID, I would argue that the politics involved in killing the systematically socially dead (such as disabled people) and the catastrophically socially dead (such as healthcare workers in crises) are different, and that the overlap here, is due to the sheer volume of infections generated (and how). In previous cases like H1N1 and SARS, the transmissions of the infections had been relatively small, and the progression of these respective viral transmissions had been much slower. Because COVID has infected and “killed” so many people, in such a short range of time, the fear of the pandemic seems to invite the state, and by proxy, health workers, to increasingly rationalize situating some people as inherently more disposable than others. Moreover, it is not like either the workers or the state will ever truly be held accountable for acting upon such ideologies. In fact, what we will have in archiving the evidence of such atrocity will be located in state data collection databases. Here, it is only of significant consideration to acknowledge that the state has chosen to reflect the deaths of disabled people within their statistical analyses amid a

pandemic, and not to prevent or respect said deaths in any meaningful way.

Troubling what it means to die in catastrophe politics

Now, I want to turn to the underlying affective politics at play within the climate of catastrophic social death I have described above. So much of my thoughts have been formed in response to the fears I, and those in community with me, feel toward health workers postCOVID. The same people who would very likely be directed to kill me, should I become infected, also feel the pain of the catastrophe and, within that, I worry about how the consequences of death happening at such a massive scale will impact the intimacies of death and dying. Specifically, I fear the pain of those who are dying alone, who wish for the presence of their family and friends, and who will never have an opportunity to say their goodbyes as they transition from life to death. I fear how their bodies will be cared for once they are no longer alive. I fear the suffering their kin will feel after they lose the right to say goodbye to their loved ones. I fear the trauma they will hold with the weight of knowing how their loved one's body were discarded. I fear how we will remember these losses. I fear the immense number of people dying will outweigh the significance and the quality of their lives as they become statistics. I fear that this catastrophe, like so many others felt by marginalized communities, will be overlooked, and that this will reaffirm to the powers that benefit from our losses that we can be forgotten.

I cannot shake my fear, and the more it grows, the more it only seems to fill me with a kind of anger and sorrow I have only recognized in the intergenerational trauma I inherited from my queer elders who lived through the onset of the AIDS pandemic (in the west), and from mad and disabled elders who have been the targets of ableist and sanist violence for their entire lives. Moreover, although I did not inherit the legacy of racial trauma (or I have, but only as a benefactor), I also acknowledge the trauma and pain of non-white communities whose experiences with

centuries of racial and colonial violence have constituted the politics of death that condition our entire social climate, and who will thus, without a doubt, similarly feel the affective shifts in the intimacies of death that I describe here. To live through COVID is to go through yet another disaster in a long list of disasters experienced by us “not-or-not-quite human” subjects (Weheliye, 2014, p. 22), and the ramifications of what it means to keep having to live through our ongoing, “deeply atemporal” state of exception (Sharpe, 2016, p. 5).

In an interview between Brian Massumi and Erin Manning (2015) featured in *Politics of Affect*; the two scholars discuss how major ecological crises, like the 2011 Fukushima Catastrophe, have dramatically shifted the politics of catastrophe. In the interview, Manning suggests that catastrophes are no longer considered horrific “exceptional” events, but rather, “ubiquitous” (p. 112). Massumi responds by acknowledging that he does not believe the culture has become desensitized to catastrophe, but rather, that the contact between ourselves and others (which once was interpersonal) has become dispersed. He contends that this dispersal signals, not the abject removal of affects related to collective trauma, grief, and suffering, but how contact sites have experienced alterations in affect (p. 113). Massumi writes:

We're absorbed in the immanence of catastrophe, always braced for it—which means it has become immanent to our field of life. That imminence-immanence is a mode of contact, of direct affective proximity, even if it occurs ‘at a distance’ through the action of the media, or more to the point, within an increasingly integrated media technology. (p. 114).

This sentiment holds true as we reflect not only on how COVID is impacting us right now but on how the catastrophes that came before it impacted, if not primed, us as well.

Namely, we are not reconciling or coping with what is happening via COVID because

catastrophe is always, and has always been, happening. Just as Massumi (2009) observes elsewhere, the source of our anxieties, that which threatens our states (nationally, physically, emotionally, spiritually, etc.) are always on the horizon, so we are never post-trauma. He specifically writes that this “threat does have an actual mode of existence: fear, as foreshadowing. Threat has an impending reality in the present. This actual reality is affective” (p. 54). In other words, our culture is hardwired to brace for threats that do not exist based on the fears we developed in response to both past traumas and fictional futures. Unlike natural disasters, however, pandemics are harder to prepare for because they occur with less frequency than, say, that of a hurricane, just as the systems that become the catastrophe zone (such as healthcare) is constantly at risk of being underfunded by the administrations that govern them (save the profitable parts, like the pharmaceutical industry). Put differently, our culture responds to the needs of the people in a pandemic by instead appealing to the nation’s economic prowess.

Further, the dispersal of contact between people during COVID has only worsened the negative impact of the pandemic on our psyches and affectual wounds. Though I am certain we will return to being allowed to say goodbye to loved ones eventually, I fear the damage will have already been done COVID has revealed on a widespread level that our culture is willing to accept the culling of specific groups in the name of a greater reward for the masses. This is not a particularly startling realization, given that this is the basic premise of eugenics. However, what is startling is how we are actively reconfiguring death - how we have translated the condition of dying into a set condition, even though we know that dying does not remove the truth that to *be actively dying* still implies that one is still *living*. Such erasure has obvious biopolitical consequences, but it also creates the conditions for a preternatural memorialization of living people. In our current state, preternatural memorialization refers to the act of pre-emptively cultivating a robust narrative about the loss of an

individual to COVID that becomes enmeshed with the rituals of grieving and responding to the wider pandemic at large.

For comparison, preternatural memorialization occurred during the early years of the AIDS pandemic, but it occurred with consent. HIV-positive people, especially queers, knew and had grown accustomed to accepting the reality that they would likely die before the state would be willing or able to intervene. Ann Cvetkovich (2003) writes of this phenomenon regarding the lesbians who became caretakers and memory holders for their terminally ill gay and MSM friends. Cvetkovich admits that the process of memorializing losses before they happen is a complicated one, noting that to memorialize something in the act of its happening runs the risk of being reductive. In that process, we lose the nuances of the circumstances of those deaths and their adjacent traumas. This point is especially prudent in relation to the current COVID-19 pandemic: Like AIDS, COVID is a population-wide crisis that has incited preternatural memorialization, but, unlike the AIDS pandemic (at least, in the west), the wide-scale grief that emerges from it is incredibly culturally specific because the people who are dying, belong to wide ranging communities (i.e., the disabled, Indigenous, poor, Black, elderly, etc.).

The issue that emerges with preternatural memorialization during COVID is that this form of memorialization is at risk of becoming a national trauma, which Cvetkovich (2003) defines as an event that stirs up world-defining [inter]national attention (p. 16). The problem with national trauma is that there is always the danger of it becoming *nationalized* and, therefore, *naturalized* trauma. The world-defining nature of such events often takes away from the very lived experiences of oppression that led to the catastrophe in question, which is astronomical in the first place. We can thus understand COVID’s body count from disabled, Black, Brown, Indigenous, migrant, poor, and elderly populations as being underscored by this logic and, more specifically, what Cvetkovich calls the “insidious and everyday forms of trauma

generated by...other forms of oppression” (p. 161). This trauma will likely not retain a high affective potency because these deaths are being subsumed and naturalized via nationalized rhetoric contextualized by western humanist ideologies. If we allow ourselves to acknowledge COVID-deaths as sequential, then we risk acknowledging COVID being a public health crisis, which can cheapen the losses of marginalized people through the generalization of their subsequent deaths.

Because many deaths are being positioned as inevitable and therefore natural, which I identify here as the consequence of the body being unable to sustain itself without intervention, the grieving and caring practice under COVID will become highly individualized. By placing the responsibility of care onto frontline health workers, many of whom are non-white, the state has already excused itself from being held fully accountable for healthcare as a set of inadequately prepared institutions. Because the state has also imposed a state of exception (that which necessitates the death of some bodies over others), health care workers will also ultimately be held unaccountable for the total losses accrued.⁸ The hospital as a zone of catastrophe is underpinned by the logic that every decision made within the confines of the zone, are those of necessity, as this zone makes every decision a “life or death” decision.

Outside zones, like gathering places or households, are not considered parts of the catastrophe zone per se but may take the blame for the widening of the catastrophe via “increased” contraction and spread. Because of this, each death is crafted to appear zone-specific, which, in turn, plays out in the media by reinforcing the importance of the individual cases highlighted therein. “A *beloved parent, grandparent, sibling, friend, co-worker...*” each death is emphasized by their attachment to their

living counterparts. The personhood of the deceased is only reconfigured posthumously when their loved ones invoke a particular memory. Hence, their death is not merely grievable because the person has died, but because those still alive, and who attribute a social or affective weight to their physical absence, miss them.

To borrow from Butler (2009), the intimacies of performing trauma and loss by those left alive in a period of catastrophe are only validated when the frames through which the performance occurs can be made intelligible (p. 7). The major framing of death during COVID is the one provided to us by the state and its regulatory bodies (primarily healthcare and the media): we have already been told that these people are *dying*, not that they are being *killed*. Here, their deaths are, again, natural, even *if* loved ones deploy the rhetoric of memorializing individuals as someone who was “gone too soon”. The performative memorialization of their loved ones is framed in ways that better contextualize the frames already established by the state, whereby posthumous recognition intends to highlight individual tragedies, not a population-wide travesty.

Concluding remarks

Removing Intimacy

As I have emphasized throughout this article, death is intimate. Dying is inevitable. But throughout time, *how* we die and [are] mourn[ed] has transformed. The politics of touch have also changed, especially now, because of the COVID-19 pandemic. Circumstances may prevent or alter the ways dead people are touched and when it is appropriate to touch them—*if* they can be touched at all. Generally, in the process of dying and in the process of preparing a dead body for disposal, touch is permissible. People often die surrounded by their families and friends, usually described as passing away, after a final goodbye (verbal and/or

⁸ As of April 19, 2021, the Ontario government has yet to be fully transparent regarding Ontario triaging protocols despite numerous recommendations made by the Triage Advisory Committee formed by ARCH Disability Law and the AODA Alliance. As a result, the current “critical care

Triage Protocol has been sent to all Ontario hospitals, and subsequent training has been offered to hospitals and doctors that urges doctors and hospitals to use it” but has not been officially endorsed by the Ontario government (ARCH Disability Law Centre, 2021).

physical) is made in proximity to the recently deceased. In normal circumstances, people who die in hospitals are often afforded these final acts of intimacy. These acts range from the relationship formed between the dying person and their conceptualization of death; the dying person, and the afterlife (if that is what they believe is waiting for them); the dying person and their caretakers; the dying person and their selected visitors, and finally, the dying person and those who will prepare their bodies when they are no longer alive. These relationships represent the many different forms of intimacy that fall under the reality of death. While they may span the range of the innately spiritual, to the physical, to the emotional, to the mental, they are all bound by caretaking.

COVID disrupts these processes through the militant surveillance and monitoring of touch. Folx in catastrophe zones are denied not only physical touch and spatial proximity with the outside world. This means that, although health workers cannot contact people outside of the catastrophe zone, they are still able to touch those who are infected. However, because of the lack of personal protective equipment, many staff are afraid to make more contact than what is strictly necessary with those who are infected and/or dying (Loriggio, 2020). They are also responsible for ensuring that visitors are prohibited from entering the catastrophe zone. While this generally makes sense because of how easy it is to contract the virus, the concern at play here is the restriction and total removal of intimacy from a space of both caretaking and dying.

Just as visitors are prohibited from contacting their loved ones in what could be their last chance to spend time together, patients are essentially being left to die alone because of the pervasive fear of contamination. With HIV/AIDS, as Cvetkovich (2003) reminds us, the fear of contamination demarcated queer (or queered) bodies to be bodies of risk and, in that process, made it so that the similarly queer were the only ones willing to interact with folx sick, dying, and/or dead from HIV or AIDS. Moreover, the trauma that manifested as a result of further

alienating infected people made regular intimacies like death and care work insidious. Speaking of trauma generally, she writes that it “makes itself felt in everyday practices and nowhere more insidiously or insistently than in converting what was once pleasure into the spectre of loss or in preventing the acknowledgement of such losses” (Cvetkovich 2003, p. 163). That is, the love in ordinary relations becomes permission to grieve what the trauma holder perceives as a loss.

Healthcare workers and patients have lost their closeness to each other and their families and because the motivation to refrain from contact is a necessity (made possible by state failure), they are, in turn, radically losing intimacies that are otherwise innate to the conditions of the hospital as a site of caretaking, while also rendering the mere existence of sick, dying, and dead bodies, into threats. Even then, as those dying are left alone, they may not have access to alternative forms of communication (i.e., through text or even video-chat) and are thus disavowed from their right to feel the more natural and ritual experiences of dying and death. People are being intubated, often without the option of saying goodbye, lucid, and in pain, knowing very well that they may not survive the experience. Even though dying is a sad event for many, knowing that oneself is being perceived negatively by others due to the fear of contamination, and being left alone as a result, can be even more heartbreaking.

In essence, what we are reckoning with the further that we move into this current health pandemic, is the total excision of the right to feel and be intimate toward each other under the premise of catastrophe politics. I began my article with a conversation on masking because the pandemic is radically shifting what it means and looks like to die, and those shifts bear significance in terms of how we relate to ourselves and one another within and through a catastrophe. That is to say, that the deaths of those from COVID are *unmasking* something darker within our world order, revealing the everyday violence that the state enacts as it handles a catastrophe, it very

well had a hand in creating, and it is important to acknowledge the brutality of these losses. Such brutality does not bode well for cultivating a greater appreciation for the intimacies of death and dying in a death-shy culture, nor does it bode well for how we relate to each other amid communities experiencing crisis, and I feel very troubled by these truths.

As we now know, many changes to care work have happened as a direct result of a total lack of regard for (many) human lives in catastrophic events. The current pandemic has been catastrophic, for instance, for those within long-term care facilities, both at the level of contraction and isolation. The marginalized communities to which I belong and can relate, are being essentially punished for trying to survive this pandemic, and as a disabled person, I am not surprised by the violence and cruelty of the state - we have been programmed to brace for a catastrophe like this before, if not always. But this has never been to the extent that it now is - to the extent that we are being stripped, *en masse*, of the right to mourn, grieve, and die. This traumatization is the direct result of systemically destroying the intimacies of care work and community, and of death and dying. There is a strong disconnect between the management of this crisis and the actual feelings of people as our affects are being managed and framed for us.

References

- Adams, D., & Erevelles, N. (2017). Unexpected spaces of confinement: Aversive technologies, intellectual disability, and “bare life.” *Punishment & Society*, 19(3), 348–365. <https://doi.org/10.1177/1462474517705147>
- Agamben, G. (1998) *Homo Sacer: Sovereign Power and Bare Life*. Redwood City, CA: Stanford University Press.
- Agamben, G. & Attell, K. (2005). *State of Exception*. University of Chicago Press.
- Alexiou, G. (2020). *Doctors Issuing Unlawful ‘Do Not Resuscitate’ Orders For Disabled COVID Patients ‘Outrageous.’* Forbes. <https://www.forbes.com/sites/gusalexiou/20/06/23/unlawful-do-not-resuscitate-orders-for-disabled-COVID-patients-outrageous/>
- ARCH Disability Law Centre. (2021, April 19). *NEWS RELEASE - FOR IMMEDIATE RELEASE - Six Bio-Ethicists on Ontario Government’s “Bioethics Table” Confirm Ongoing Concerns Raised by Disability Organizations regarding the Discriminatory and Secret Plans for the Triaging of Critical Care*. ARCH Disability Law Centre. <https://archdisabilitylaw.ca/news-release-for-immediate-release-six-bio-ethicists-on-ontario-governments-bioethics-table-confirm-ongoing-concerns-raised-by-disability-organizations-regarding-the-dis/>
- ARCH Disability Law. (2020, April 8). *OPEN LETTER: Ontario’s COVID-19 Triage Protocol* [Personal communication]. <https://archdisabilitylaw.ca/wp-content/uploads/2020/04/April-8-2020-Open-Letter-Ontarios-COVID-19-Triage-Protocol-PDF.pdf>
- Ayoubkhani, D., & Bosworth, M. (2021, February 11). *Updated estimates of coronavirus (COVID-19) related deaths by disability status, England—Office for National Statistics*. Office for National Statistics. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronavirusCOVID19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020#risk-of-death-involving-COVID-19-by-self-reported-disability-status>
- Butler, J. (2009). Introduction: Precarious Life, Grievable Life. In *Frames of War: When is Life Grievable?* Verso. https://edisciplinas.usp.br/pluginfile.php/4098884/mod_resource/content/1/Butler%20%282009%29%20Precarious%20life%20-%20grievable%20life.pdf
- Campbell, F. K. (2008). Refusing Able(ness): A Preliminary Conversation about Ableism. *M/C Journal*, 11(3), Article 3. <https://doi.org/10.5204/mcj.46>
- Coronavirus: Autistic support group “told it needed DNR orders.” (2020). *BBC News*. <https://www.bbc.com/news/uk-england-somerset-52217868>
- Cvetkovich, A. (2003) *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures*. Durham, NC: Duke University Press. ISBN 0-8223-3076-8
- Downey, A. (2009). Zones of Indistinction: Giorgio Agamben’s ‘Bare Life’ and the Politics of Aesthetics. *Third Text*, 23(2), 109–125. doi.org/10.1080/09528820902840581
- Goodley, D., Lawthom, R. & Runswick-Cole, K. (2014) Dis/ability and austerity: beyond work and slow death, *Disability & Society*, 29:6, 980–984, DOI: [10.1080/09687599.2014.920125](https://doi.org/10.1080/09687599.2014.920125)
- Grue, L. (2010). Eugenics and euthanasia – then and now. *Scandinavian Journal of Disability Research*, 12(1), 33–45. <https://doi.org/10.1080/15017410903076776>
- Loriggio, P. (2020). ‘No one wants to hug me’: What it’s like to be an essential worker on the front lines of COVID. *National Post*. <https://nationalpost.com/news/canada/COVID-19-essential-workers-coronavirus>
- Massumi, B. (2015). *Politics of Affect*. Polity Press.
- Massumi, B. (2009) “The Future Birth of the Affective Fact: The Political Ontology of Threat” *The Affect Theory Reader*, pp. 52–70., doi:10.1215/9780822393047-002. Duke University Press. Durham and London.

- McKitty v. Hayani, 2019, ONCA 805.
 New York State Task Force on Life and the Law New York State Department of Health. (2015). *Ventilator Allocation Guidelines*. New York State Health Commission.
- Piepzna-Samaraisnha, L.L. (2018). *Care Dreaming Disability Justice Work*. Vancouver: Arsenal Pulp Press.
- Reeve, D. (2009). Biopolitics and bare life: Does the impaired body provide contemporary examples of homo sacer? In *Arguing about Disability: Philosophical perspectives* (pp. 203–217). Routledge.
- Sharpe, C. (2016). *In the Wake: On Blackness and Being*. Duke University Press.
- Tapper, J. (2021). Fury at ‘do not resuscitate’ notices given to COVID patients with learning disabilities. *The Guardian*.
<https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-COVID-19-patients-with-learning-difficulties>
- Tennessee Altered Standards of Care Workgroup. (2016). *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee*. Minnesota Department of Health.
- Washington, P. (2018) *Brain death is death: Ontario court provides important clarification on definition of death*. Norton Rose Fulbright:
<https://www.nortonrosefulbright.com/en/knowledge/publications/4553feea/brain-death-is-death-ontario-court-provides-important-clarification-on-definition-of-death>
- Weheliye, A. (2014). *Habeas Viscus: Racializing Assemblages, Biopolitics, and Black Feminist Theories of the Human*. Duke University Press.
- Woodard, V. (2014). *The Delectable Negro: Human consumption and homoeroticism within U.S. slave culture*. New York University Press.

Acknowledgments

To the sick, dying and dead among us, I love you.

Author Biography

SK Sabada is a white, nonbinary, mad, disabled PhD student in Gender, Feminist and Women's Studies at York University. Their own work is situated at the intersections of queer theory, mad studies, disability studies, trans studies and performance studies. Their own research focuses on questions related to how and why mad and trans people die and how these deaths require critical interrogation that moves beyond the mere acceptance of their happenings. It is SK's wish that by developing a notion of the critical intimacies of death and dying and by critically caring about how we respond to and interact with death in a death-shy culture, that we can collectively make the ways everyone lives and dies, better.