

## **A Reflection on Racial Injustice and (Black) Anticipatory Grief Compounded by COVID-19**

Rai Reece

### **For Correspondence:**

Dr. Rai Reece

Department of Sociology, Ryerson University.

Third floor, Jorgenson Hall

350 Victoria Street, Toronto, ON, M5B 2K3

Email: [rreece@ryerson.ca](mailto:rreece@ryerson.ca)

### **Abstract**

This reflection is a deeply intimate and personal expression about living through an unprecedented moment in time. The impact of a global health crisis amidst an ongoing search for racial justice has made this writing one of the most profound experiences that I have ever encountered. It is within this work that I found a silent strength to carry on my work for a better, more just tomorrow – a world where Black, Indigenous and all racialized people experience true emancipation in all aspects of their lives.

**Keywords:** Anticipatory Grief, COVID-19, Black Lives Matter, Racism, Dementia

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On September 8, 2013 I wrote the following:

### ***A Precursor to Dementia***

*This morning was hard. I woke up to feed my new baby, who by the way has been sleeping through the night since she was 7 weeks and will be 7 months old next week. My back hurt, still remnants from my C-section. I remember looking at the clock and thinking 'it's 7.24 am and maybe most people have already started their day, or some are ending their night shift.' I needed to get going so decided that today would be a productive day in that I have so many things to do. There is a constant 'day-to-day' grind that I enjoy about my life – I am familiar and comfortable in 'busy'ness. I found myself remembering a time not so long ago when life felt just as busy, but not so overwhelming. I have never been one to lament about why things happen in my life the way that they do. I don't ask 'why me' because quite frankly 'why not me.' What I did not see coming was a diagnosis of dementia for my father, and a rapid downward progression that would take place within three months.*

### ***Chaos, Fear, Acceptance of a “New Normal”***

*My new baby girl was born on Thursday February 28, 2013 at 12.37 pm. Under any other circumstance my entire blood related family would have been there. However, my father was absent and also a no show the next day. Now it was Saturday. Since this was my second C-section, I already knew that the faster I could get on my feet walking around, the sooner I would be able to go home. When my doc came to check on me, she told me that I can go home one day early since I was already up and moving, and she was pleased with my progress. I was elated to be able to go home that Saturday. My elation was soon subdued by the fact that at the back of my mind, I was angry. Where was my father? I grew up an only child to*

*immigrant West Indian parents. I have always been extremely close to both of them and at this very moment, I could not understand why my father was not there at the hospital for the birth of his second grandchild.*

*Why wasn't my father at the hospital? Partly he was confused about the event that had just taken place. At that time, he knew what was happening, but his cognitive abilities to process what he should do in the moment was waning. As family members, we had absolutely no idea what was going on. My father was in the early stages of his illness, and the beast was not yet at full throttle; my father's diminishing cognitive abilities were still intertwined with moments of clarity and cognitive understanding. This is what makes a diagnosis of dementia so challenging – it is not always apparent that something is wrong. We all may have at times forgotten where we put our keys or forgotten to pick something up at the grocery store. However, usually we can easily recollect what has been forgotten and we don't deny what has happened. It's now 6 months into my father's diagnosis. I have had to courageously find a way to explain to my 4-year-old why her Papa no longer plays with her; and why he doesn't interact with her little sister. My heart breaks almost every day as I watch my father diminish a little bit more. I watch my mother work tirelessly to maintain a sense of “normalcy” in their home; and I watch her and myself struggle with frustration when we are full and tired. We still love and laugh and every now and then, I see a glimpse of my father – his witty banter comforting my soul and figuratively wiping my tears. Conversely, my heart swells with pride when my 4-year-old directs her Papa upstairs or holds his hand to guide him through the house.*

*Dementia is a beast. It ever so slowly creeps into your body – sly, clever, sharp, and witty. It fools you and the body it has*

*snatched. It is deceptive and as it progresses, you need to try and make peace and friends with it. Because in the end or the beginning, a diagnosis of dementia means it will be a mainstay in your life, and it will also mean the creation of a “new normal” for you as a caregiver and the person afflicted with the illness. The beast is witty too – mostly because in my reality, I engage in witty playful banter with my father as one form of the little communication we have now. The progression of this illness has slowly taken away my father’s verbal skills. And instead of being angry at this beast, I have tried to beat it at its own game and become friends with it, because as it slowly takes my father, I would rather have a friend than an enemy.*

### **A Precursor to Anticipatory Grief**

Since that writing almost seven years ago, I have come to learn that my ongoing experience with my father’s dementia can be categorized as anticipatory grief. The “complex phenomenon of grief” (Finch, 2020) means that how we conceptualize loss is contingent on a myriad of factors – some within our control and some not. Grief in general is numbing and on a continuum. It comes in waves depending on the suddenness of loss, or the experience of a prolonged illness that a loved one endures. Anticipatory Grief (AG) is defined as a “phenomenon seen in caregivers receiving a forewarning or expecting the impending death as opposed to bereavement by sudden death” (see Nielson et al., 2016 citing Fulton, 2003; Gerber et al., 1975; Sweeting and Gilhooly, 1990). Although AG is usually associated with folks with terminal illnesses such as cancer, and less associated with unique diagnosis such as Alzheimer’s or dementia – illnesses specific to the progression and deterioration of both cognitive and physical abilities (Holley and Mast, 2009), there have been studies that have examined the impact of anticipatory grief specific to dementia (Cheung et al.,

2018; Holley and Mast, 2010; Lewis and McBride, 2004). When my father was diagnosed with dementia in March of 2013, my mother and I initially had no idea what was going on with him. His behaviour was erratic and moody; he struggled to find his words; he reported an episode where his vision went blurry; he left the house at all hours to go to work (he had been retired for 15 years by the time of his diagnosis). I was the first to notice that something was “off” with my father when I was about six months pregnant with my first child in 2008. One afternoon, I went upstairs to check on my father because he was taking longer than usual to come downstairs from his morning routine. When I went upstairs to knock on his bedroom door, it was already ajar, and I noticed him drinking tap water from the toothbrush holder that usually takes up residence only for toothbrushes on the bathroom counter. He had a separate rinse-cup that he always used. Odd behaviour indeed, so I called out to him, asking him if he was okay and he replied in the affirmative. I told him to “make haste” – a Caribbean reference to “hurry up” and come downstairs. When I told my mom, she didn’t seem particularly alarmed by his behaviour since he seemed fine and like himself when he finally did enter the kitchen. A few hours later, he had a stroke.

The emergency room physician told me that what my father experienced at home weeks earlier was likely was a Transient Ischemic Attack (TIA), commonly referred to as a mini-stroke (American Stroke Foundation, n/d). TIA’s are considered warning signs of an impending stroke, and it is imperative that people who experience them seek medical attention immediately. Having no knowledge of the warning signs of a TIA, I realized the odd behaviour that my father was exhibiting weeks earlier was the precursor to the eventual stroke that he would experience. His time in the hospital was

marked by a barrage of tests; mostly regarding his cognitive abilities, eventually leading to him being discharged with the understanding that he was fortunate his stroke did not appear to have any immediate concerns – his speech and mobility were intact, but the underlying vascular dimension of his brain function was irreversibly damaged.

Our return home was eventful because we were relieved (falsely), and comforted that my father appeared to be fine. He had received stroke medication from the emergency room doctor, and after following up with his family doctor, as a family we were eager to feel “normal”, and so we embraced his “normalness” as a false comfort. By the time my first child was born, the joy of the birth of my parent’s first grandchild diminished lingering fears that abounded regarding any residual effects of my father’s stroke. I settled into motherhood; he settled into grandfather-hood, and we settled into life.

### **(Black) Anticipatory Grief**

The metaphorical bracketing of Blackness and Black bodies as abhorrent demonstrates that the proliferation and maintenance of white supremacy has worked to erase, deny and delegitimize the fluidity of Blackness as whole, beautiful and worth fighting for. Within the current socio-political climate, images of Black death and grief have saturated social media, news outlets and the internet (see Elbaum, 2020; Tisby, 2020). The continued threat of police brutality, supported by historical and current examples of surveillance of Black bodies have resulted in mass incarceration, blatant abuse, and death. This visceral reality has become mainstay facets of conversation that many Black folks have experienced for years.

The rallying cries for Black lives to matter and a divestment from exorbitant police budgets to an investment in community care and equity for Black, Indigenous and racialized communities have resulted in unprecedented local and global social justice and civil right movements. Ibram X. Kendi (2020) has noted the correlation between COVID-19 and police brutality, calling these racial disparities an example of the racial pandemic within the health pandemic. Anticipatory Grief in many ways has been a mainstay of a racial pandemic that has been in effect for over 400 years. Moreover, anticipatory grief is interconnected and impacted by other social phenomena in our environments such as racism, sexism, classism and ableism. These intersectional experiences have highlighted further discussions about the implications of Mad<sup>1</sup>, Deaf and disabled bodies as central to the movement for Black lives:

Black Mad, Deaf and disabled folks have been at the forefront of this movement and are leading the charge through disability justice organizing – something the movement for Black lives is predicated on. As people all over the world cry out to defund the police and stop the brutality that they enforce on Black and Indigenous communities, it’s been important to highlight the disastrous effects of policing and prisons on Mad, Deaf and disabled people. The majority of Black people we read about in the news who have been killed by the police have been killed because they were Black and Mad. Their Madness was a key factor in the killings. Black and Indigenous Mad people are vulnerable to police wellness checks that often result in fatalities or forced

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<sup>1</sup> ‘Mad’ is terminology often used by folks who have had experiences with psychiatric hospitalization.

psychiatric detention in a jail or locked ward (Ware, n/d).

Ware highlights that central to the movement for Black Lives Matter, is the transformative justice-praxis that all Black lives ought to matter in the fight for social justice and equality.

I remember acutely when the bracketing of my anticipatory grief began. In 2012, the Black Lives Matter movement was created as a direct response to the killing of 17-year-old Trayvon Martin in Florida, United States. I didn't know at that time that the impact of his death and my father's diagnosis a little over one year later would become so inextricably linked. Additionally, I did not realize the impact of grief as interconnected to racial injustice would create wounds so deep and begin the process of my own compartmentalizing of kinship grief. As I searched desperately for information about dementia and tried to understand the so-called difference - at least medically - between dementia and Alzheimer's, there was a shroud of secrecy that began to envelop my family dynamic. In order to fully understand the premise behind this secrecy, a brief historical evaluation of some key moments regarding the imprint of colonial slavery of Black people as connected to stigma and shame is warranted. Stolen enslaved Africans arrived in Canada in the 17th and 18th century (Canada, 2020). Between 1763 and 1865, most Black people migrating to Canada were fleeing slavery in the United States (Walker, 2015). In 1910, the Canadian government implemented a moratorium on immigration from "undesirable races" and implemented an *Immigration Act* that prevented Black people from entering Canada for the next few decades (Canada, 2020). During the 1960s and 70s, the reigns of immigration slightly loosened, and Black people from the Caribbean began arriving in Canada at a more

fervent rate. In particular, the creation of the *West Indian Domestic Scheme* (1955), allowed single women (18-35 years old) to work in Canada as domestics for one year before being granted immigrant status (*Ibid*, 2020). In pursuit of some kind of economic consistency many Black Caribbean women left behind their child/ren in the islands and became domestics and/or caregivers for families abroad. The plight of racism and weaponized sexism as engendered upon the bodies of Black women leaving their families to care for other, usually white families was the very enacting of systemic racialized and gendered state violence. As many Caribbean families immigrated to Canada, the promise of a better life meant living up to the Canadian dream of travelling to "foreign" and achieving success (buy a house and remit barrels of goods back "home"). For many Black people who were able to enter Canada during the late 1960s and 1970's, being Black in Canada also meant pledging eternal allegiance to Pierre Elliot Trudeau's liberal party for paving the way for Caribbean folks to come to Canada. The language of acceptance in Canada also meant not talking openly about the racism many experienced on the job, or not talking about the polite forms of racism that diminished educational qualifications, or continuing to smile politely when folks asked what your "first" or "native" language was because you had a prominent Caribbean accent. Many Black people in Canada experienced racism via the specific ghettoizing of Black women as domestics and personal support workers and the pervasive racial profiling that young Black men and women were subject to. Given all of this, Caribbean Black folks were definitely not going to talk about the struggle and grief of a family member with a cognitive impairment.

My parents experienced double-migration; meaning they immigrated from the Caribbean to the United Kingdom and

then to Canada. By the time they settled into life in Toronto, the more apparent it became that they were not seen as the “model minorities” profitable for the political building of this nation, but rather they were viewed as national domestics whose labour would churn the economic wheels of contemporary colonial capitalism. Moreover, systemic racism taught Black people that success meant silence – white people could talk about their struggles because there were places of help, doctors and nurses who looked like them and would help them in times of crisis. White people are given permission to grieve. Whatever permutations and configurations that grief undertook for my family, the broader socio-cultural landscape of racism and specifically anti-Black racism dictated that the grieving for a life lost with my father was to be done in silence.

In 2013 we received the official diagnosis that my father had Vascular Dementia as brought on by the stroke he had in 2008. In order to protect him, we only told very close family friends. With our strategically guided direction, my father ‘disappeared’ from life while he was still alive. As his illness progressed, I witnessed the toll his caregiving took on my mother as she became his primary caregiver. We sought support with the Toronto Community Care Access Centre, who assisted us in finding local day programs and respite homes when my mom and I needed a break. As his eventual decline led to his loss of mobility, we told no one of his entry into a nursing home, other than very close family friends. When long-time neighbours noticed they hadn’t seen him in months, we lied and said he was fine and just taking it easy. When that lie would not hold up anymore, we eventually said he was placed in a nursing home. We decided that we would never disclose the name of the nursing home he lives in, for fear that folks who wanted to be “in our business” would secretly try and visit him to “fess”

(Caribbean term for nosiness) and see how dementia had taken a toll on him. We did not see this as shame, rather we viewed these decisions as measures to protect his dignity. We experienced pitiful glances and disappointing verbiage spewed towards us that we, or more pointedly my mother, had “failed” as a Black Caribbean wife to take care of her husband. This latter judgment hurt the most. Caribbean life dictates that Black folks take care of each other. With the lack of nursing home facilities located on numerous Caribbean islands, historically, when folks enter their twilight years, other family members take care of them. There is no abundance of Long-Term Care (LTC) facilities to place family members in. Moreover, there is no government subsidized infrastructure to help supplement the cost of long-term care. On many Caribbean islands, out of necessity and cultural practices of care, Black folks with cognitive impairments such as dementia stay and die at home.

### **Black Health Matters: Racial Politics in a Health Crisis**

The Novel Coronavirus (COVID-19) was initially hailed in the media as the great equalizer. Mainstream rhetoric about the non-discriminatory transmission of the virus permeated media and news outlets. The consistent messaging was that regardless of race, class, or gender, all were susceptible to COVID-19 transmission. Then the narrative slowly began to shift. I sat home one evening overwhelmed by reading staggering statistics about the increasing numbers of COVID-19 cases among Black folks, and how the virus was ravaging Black communities in the United States (see Evans, 2020). At one point in April 2020, Black Americans accounted for 42% of all COVID-19 related deaths (Stafford et al., 2020). However, here in Canada, Ontario government officials such as Health Minister Christine Elliot and Chief Medical Officer of Health Dr. David

Williams, were reluctant to acknowledge the glaring disproportional impact of COVID-19 on racialized communities. While they continued to postulate that within the COVID-19 chaos, all lives were susceptible, and that collection of specific race-based health data in relation to COVID-19 was unnecessary, increasing numbers of Black and other racialized folks were contracting the virus. In response to this, on April 18th, 2020, Dr. Roberta K. Timothy, an Assistant Professor in the Dalla Lana School of Public Health at the University of Toronto and I organized and co-hosted the first ever webinar in Canada about Black Health and COVID-19. The two-hour forum titled *Black Health Matters: Responding to COVID-19* brought together frontline workers, academics, and a medical doctor to discuss the importance of race-based data collection and the lack of response to the crisis and its disproportionate impact on racialized communities by the Canadian government. We had ignited a switch; what began as a slow burning fire of denial regarding systemic racism in healthcare by government officials, grew to a national debate about socio-economic access and racial discrimination in healthcare. Across the country in Alberta, Manitoba, Ontario, Nova Scotia and other provinces, folks were beginning to talk about the link between socio-economic status and access to healthcare. On June 3<sup>rd</sup> 2020, Andrea Horwath, leader of Ontario's Opposition NDP, called on Ontario Premier Doug Ford to issue an emergency order to collect race-based health-care data (Delaire, 2020). However, by July 2020 there still has been no coordinated federal effort to mandatorily collect race-based data when people are diagnosed with COVID-19 or when contact tracing. As Marla MacInnis, Media Relations Advisor for the Government of Nova Scotia stated, "some race-based data is collected if individuals choose to self-identify to Public

Health. However, there is no requirement to provide this information and therefore it isn't reported on" (quoted in Field and Quon, 2020).

Research investigating systemic racism and racial barriers to healthcare has been well documented (Baldwin, 2003; Burnes et al., 2004; Das and Gaffney, 2015; Elliot, 2020; Freeman and Payne, 2000; Harawa and Ford, 2009; Tashiro, 2005; Watts, 2003). The denial of systemic racism in Canada, and more specifically the wide gap in economic disparities between white people and racialized folks is glaring, but this discussion is not new. In fact, in 2001 Grace-Edward Galabuzi published a seminal report where he underscored that the relationship between socio-economic status and health are interconnected since poor health is one of the indicators that contribute to an individual's household's poverty (Halwani, 2004). More specifically in Canada, health disparities (see Jiménez-Rubio et al., 2008), and health inequities specific to Black people (Patterson and Veenstra, 2016; Rodney and Copeland, 2009) and Indigenous populations (Bethune et al, 2018; Frohlich et al., 2006) are alarming. In the United States, Wingfield (2020) has documented the impact of COVID-19 on Black healthcare workers. Similarly, in Canada, given the disproportionate number of racialized women (mostly Filipino, and Black African and Caribbean women) who work as Personal Support Workers (PSWs) in LTC facilities, healthcare advocates have argued that "[w]e know anecdotally that racialized communities are over-represented in the number of people who have come into contact with COVID-19...you can look at it from the point of view of who has precarious employment? Who is in the essential workers category? Who is over-represented on the front lines?" (Neethan Shan quoted in Delaire, 2020). At the time of this writing, in Canada of the 16 healthcare workers who

have died from COVID-19, nine have been Personal Support Workers (CFNU, 2020). The reported cases among residents and staff have been chilling: on July 7, 2020, Ryerson University's National Institute of Ageing reported "more than 18,000 cases and 6,851 deaths among residents of long-term care (LTC) and retirement homes (RH) in Canada, as well as almost 10,000 staff cases and 16 deaths" (CFHI, 2020). These stats, however, are not disaggregated by race. Further, a recent report released June 2020 by the Royal Society of Canada titled *Restoring Trust: COVID-19 and The Future of Long-Term Care* found that "Canadian nursing homes have generally been able to "just manage." However, just managing is not adequate" (Estabrooks et al., 2020, p. 8). The report details how Canada was failing older adults in LTC facilities long before the COVID-19 pandemic, and that incredible numbers of older adult deaths in LTC facilities actually mirror our lack of diligent care for older adults in general, and has caused emotional, physical and mental harm to an ageing population. Moreover, the report makes glaring that "...disparities and compounding vulnerabilities among both residents and staff, such as race, ethnicity, language, gender identity, guardianship status, socioeconomic status, religion, physical or intellectual disability status, and trauma history screening" (*Ibid*, 2020, p. 8) are critical to restoring trust to residents and staff who in LTC facilities.

Between March and May of 2020, there was an explosion of COVID-19 cases in LTC facilities in Canada, with Quebec and Ontario being the hardest hit. In May 2020, the Canadian Institute for Health Information reported that, "Canada's long-term care (LTC) sector has been especially hard hit by the COVID-19 pandemic. More than 840 outbreaks have been reported in LTC facilities and retirement homes, accounting for more than 80% of all COVID-19 deaths

in the country" (CIHI, 2020, p. 1). What happened (or did not happen) to contribute to such staggering numbers? Given the vulnerability of older adults and the precarity of frontline work in LTC facilities, why were so many facilities slow to implement restriction measures? Why were most LTC facilities not equipped with crisis intervention teams and specialists? For example, the Norwalk (Norovirus) tends to frequently rear its head in many LTC facilities and is easily transmitted. Given that lessons (seemingly) were learned from the 2003 outbreak of the Severe Acute Respiratory Syndrome (SARS) – a cousin to COVID-19 – we could presume that the Ministry of Long-term Care would have policy guidelines and protocols for the most vulnerable in our society. When this toll was taking place, I remembered my late maternal grandmother's words, "nobody wants you when you're old" – and as the number of transmissions kept rising day after day, I shuddered to think about how her words were coming to pass. As LTC facilities buckled under the weight of the realization that they did not have the capacity to manage and contain the transmission of the virus, physical distance regulations added another layer of emotional and mental harm for residents and family members now cut off immediately with little communication from LTC facilities about protocols and procedures of care for their loved ones. We made numerous calls that remained unanswered. When we did finally get through, we were often placed on hold by a receptionist who had no additional information other than "visits were restricted." I could not find out the number of cases on my father's floor, or even how many residents and staff had tested positive. We were given no information about the process for testing and how frequently residents would be tested given the rising numbers of confirmed COVID-19 cases. My level of frustration grew exponentially, as we worried



about my father's well-being. Finally, after several weeks of calling, we began to receive pre-recorded voice messages about the status of his LTC facility. These messages provided quantitatively the number of residents and staff who tested positive for COVID-19. The recordings provided no indication of a care plan for individual families and my follow-up phone call garnered no response when I asked about my father. He is "fine" they told me – they were in crisis mode with no crisis management team in place, and no time to coddle me or soothe my emotional state. It was not until I left a "spirited" message one day that I finally received a call back from a manager who set up Facetime "visits" between my family and my father. Although I was glad to see him, I longed to caress his hand, play some calypso music for him and sit by his side. I thought about the many residents who did not have anyone to advocate for them, how being alone during this incredible time of isolation would inevitably heighten their emotional and mental distress. As families like mine and others struggled for information about our loved ones; as frontline worker burnout and fatigue took hold; as residents in LTC facilities died alone; and as family members prepared zoom funerals, we held and embodied all of this grief while trying to carve out an existence of hope for a more just and equitable society where Black lives could not only matter, but where Black lives could thrive and be liberated.

### **The Wages of Black Death**

It is evident that systemic racism and white supremacy make glaringly evident that the most disenfranchised people in our society (Black, Indigenous and racialized people, Mad, Deaf and disabled people, and incarcerated people), have been disproportionately impacted by COVID-19. In addition to wading through the everyday changing elements, soundbites and

misinformation about COVID-19, the wages of Black death re-surfaced yet again as evidenced by police brutality. As images and horrendous video graphically depicted Minneapolis Officer Derek Chauvin taking life from George Floyd's body, rallying cries against police violence engulfed Canadian media outlets. Moreover, the intersectional nexus of gender and racism beat slowly as folks (finally) put together rallying crises around the death of Breonna Taylor – a Black woman who was killed by the police on March 13<sup>th</sup>, 2020 in Kentucky, United States a little over two months before the death of George Floyd. Outrage over her death - which was just as egregious and violent - seemed muted in comparison. I grieved for another Black woman violently killed at the hands of the state; I grieved because maybe, just maybe because of her gender, her death didn't gain as much traction as Floyd's. The deaths of an Afro-Indigenous woman Regis Korchinski-Paquet, a South Asian man Ejaz Choudry, and Indigenous man and woman Rodney Levi and Chantel Moore respectively, all involving police, mobilized individuals and communities in unprecedented ways never seen before in Canada or globally. These deaths and resulting grief have been compounded by COVID-19 - and it is here that we witness grief mobilizing into social movement and revolutionary resistance (see Colebrook, 2020). Yet, literature discussing racial injustice in Canada (see Tanovich, 2008 for an extensive overview of racial injustice in Canada; and Cesaroni, 2019), and the United States (Corbould, 2020; Gutmann, 1995; Hanson and Hanson, 2006; Robbins, 2005; Wrigley-Field, 2020), has been documented for years. In Canada and globally, discussions about anti-Black and anti-Indigenous systemic racism have finally come to the forefront. While some white folks struggled to come up with a definition of systemic racism, including some even denying its

existence (for example, Canadian politicians Doug Ford, Andrew Sheer, and Stockwell Day; leaders of Federal police factions RCMP Commissioner Brenda Lucki, RCMP Deputy Commissioner in Alberta Curtis Zabolcki, all denied the existence of systemic racism in Canada), Black, Indigenous and other racialized folks now had to grapple with another dimension of grief, pain and loss.

The intersectional dimension of living through a continuous racial pandemic within a health pandemic is messy – it is the kind of entanglement where trying to envision an aftermath within the current state of a crisis seems not only daunting but physically, emotionally, psychologically and mentally exhausting. Many people are experiencing anticipatory grief in relation to a health crisis, but people are also wrestling with anticipatory grief in correlation with the loss of a job, their small business, their personal safety - as we have seen with increased incidences of domestic violence (see Bradbury-Jones and Isham, 2020; Kumar, 2020; Sharma and Borah, 2020) - and with the fragility of their mental health. Further, anticipatory grief has compounded this crisis where the undercurrent of economic and social well-being uncertainty has been magnified by forcing people to adapt to new ways of mourning (Farahmandnia et al., 2020; Mayland et al., 2020; Scott, 2020; Weir, 2020; Zhai and Du, 2020). This entanglement is grief-stricken by the longing to see my father face-to-face, perhaps touch his hand and brush his hair and simultaneously grapple with staying attuned with my work as a scholar-activist. I have not had any days when I am angry (rather, I am often sad) at the situation my father is in; I have had countless days when I am angry at racial injustice. I have been angry that the system of racism has afflicted the lives of Black and racialized folks who have experienced COVID-19 directly or relatedly. I am angry at the fact that there are 50 ethno-

culturally focused LTC facilities in Ontario (Dziedzic, 2016), and not one specifically caters to Black, African or Caribbean older adults in the way that there are LTC facilities for other racialized and ethnic groups in Canada. Ethno-racial community circles of care are invaluable to the continuation and transference of cultural nuances when older adults move from their home to a LTC facility. Older adults transitioning to LTC facilities need to feel safe, and actively embedding tangible reminders of their ethno-racial heritage is an indelible supportive mechanism that can help ease them into a new physical space that often comes with confusion, fear and uncertainty. Circles of care that import cultural and racial cues can ease this tension. I am angry at this invisibility. In particular, Toronto already has a number of LTC facilities that cater to specific racial groups such as *Yee Hong* and *Mon Sheon* for the Chinese population, and other cultural groups such as the *Hellenic Home* for the Greek community, *The Villa Colombo* for members of the Italian community, the *Suomi-Koti* for the Finnish population and *Baycrest Centre* for the Jewish Community (Kay, 2012). Finding an LTC facility with specific language and ethnocultural care is challenging (see Um's 2016 Wellesley Institute report, that indicated that people who apply to ethnocultural nursing homes in the Greater Toronto Area had to wait approximately six months longer than those who applied to mainstream non-ethnocultural specific homes). As a Black family, in addition to the importance of physical, emotional and psycho-social well-being for my father, we would at the very least like the option of an ethno-racial community circle of care that would understand the cultural and racial significance of Black hair, Black music, and Caribbean/African food – these elements that also nourish the souls of Black folks.

### **Un-bracketing my Grief**

It was a close friend of mine who lost her beloved mother and subsequently attended bereavement counselling who introduced me to the concept of anticipatory grief. Before her mother's death from kidney cancer, she grieved the loss of having control over something that was imminent; she grieved the movement of her mother into palliative care, and she eventually grieved the death of her mother. When my father became ill, I remember talking to her about this constant feeling and anticipation for something bad to happen. Particularly, as his illness progressed and he became non-verbal and immobile due to muscle atrophy, I struggled and still struggle with pervasive thoughts; that every time the phone rings, it is someone on the other end telling me what I have been trying to psychologically prepare myself for, for years, that yet I know there is no preparation for. She explained to me that what I was experiencing was anticipatory grief and the beginning of a phenomenon of grief that would likely engulf my existence until.... - words too difficult to actually write because they reveal a finality I have yet to come to terms with even though I have been anticipating and consuming this grief for years. I have come to terms with the actuality that my father is a sick disabled Black body. Where previously my mother and I could regularly visit him twice a week, since March of this year, like dementia, the inception of physical distancing has denied us access to visit with my father. As of this writing, while other nursing homes in Toronto have opened up and allowed visits under strict supervision, visitors to my father's nursing home are still restricted. I have learned not to share my grief and pain of his diagnosis publicly – and this work is the first departure from that positionality, and from protection of my grief. I have learned to try and be patient with the Coronavirus and its resultant impacts, in the hope that I will not have to engage in an

internal psychological war of guilt versus the actual potency of a deadly virus – a war that I will likely lose. I am working to embrace my anticipatory grief as a journey, rather than a deficit, and accept the fact that although I cannot visit with my father, this does not mean I let him down. For years, I learned to bracket my grief, but this writing is the un-bracketing of that grief while continuing to grieve racial injustice in the hope for liberation for all Black people everywhere.

### **Recommendations**

Over the past few years, there has been promising research developments in the field of public health that have provided a framework for moving beyond merely documenting health disparities, to examining the way in which Critical Race Theory can accelerate the elimination of racism in public health (see Butler et al., 2018; Cross, 2018; Ford and Airhihenbuwa, 2010, 2018). These contributions to research cross-pollinate nicely with the scope of the work presented here in order to eradicate the complexities of racism in healthcare. The following are recommendations that have been derived with the aforementioned in mind.

1. This paper articulates the importance of ethno-racial specific community circles of care, the entanglement of anticipatory grief and racial trauma, and the intersectional impact of these elements on older adults and their caregivers (family and PSWs). An important aspect of care for older adults in general, and specifically racialized older adults, is understanding the significance of ethno-racial cultural elements that can aid in supporting transitions to LTC facilities for new residents and reminders of ethno-racial cultural comfort for current residents. Given this identification, it is recommended that specific funding for LTC facilities for African/Black/Caribbean older adults be established.

2. The lack of support and feelings of isolation that my family experienced was compounded by the lack of ethno-racial specific grief support specific to our racial background. It is important to recognize the ways in which racism impacts access to grief support, resulting in internalized and personalized struggles of grief and racial trauma. It is recommended that issues of anti-Black systemic racism and an understanding of socio-economic white supremacy, power and privilege be mandatory best practices incorporated in those administering grief support (i.e., counsellors, therapists, Social Workers etc.).

3. Given the historical permutations of colonial violence and the impact of anti-Black racism, it is critical that geriatric care training for Personal Support Work (PSWs) acknowledge the pervasive ways in which white bodies have become the standard of care that all other (read: racialized bodies) deviate from. It is recommended that policy and practice re: anti-Black racism and systemic racism address this pervasive healthcare ideology in their respective training. Further, it should be noted that research and policies that address racial and ethnic disparities in healthcare, as well as our wider society, can be intrusive due to the historical ways in which Black people and their communities have been pathologized. Research involving Black people has not been conducted in an ethical, inclusive manner. It is critical that any policy initiatives be developed and grounded in critical race and circle of care analysis, and that this work be conducted in an empowering manner so as not to disrupt, fracture or cause harm to the physical, mental, emotional and psychological well-being of racialized individuals and families.

4. The impact of COVID-19 disproportionately affected Black and other racialized communities. It is recommended that the Canadian government collect race-

based data on the number of people who contracted COVID-19 and that this data also be disaggregated by age and place of residence, in order to capture the number of older adults living in LTC facilities or those who may be residing with family caregivers. It should also be noted that the collection of data act as a starting point, rather than a solution to racial disparities and inequities in healthcare.

5. COVID-19 has had a detrimental impact on the psycho-social well-being of PSWs and other frontline staff, most of whom are racialized women. It is recommended that the government provide funding for grief counselling, racial trauma (see the work of Dr. Jamila Holcomb) and/or other identifiable supports for this group in order for PSWs and other frontline staff to work towards emotional, psychological and mental-health healing due to the devastating toll that working within COVID-19 conditions may have caused for them. Please note that given recommendation #2, it is also recommended that this support be ethno-racial and culturally specific.

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**Author Bio:**

**Dr. Rai Reece** is an Assistant Professor in the Department of Sociology at Ryerson University. She holds a PhD in Women's Studies from York University. As an interdisciplinary scholar-activist, her work examines how carceral processes in Canada are organized and maintained by historical and contemporary narratives and practices of colonial violence specific to anti-Black and anti-Indigenous racism. More broadly, her work explores the intersection of punishment and misogynoir as legally and socially enacted via governance and white settler capitalism. A central feature of her work explores how community-based ethnographic pedagogy can be a tool for social activism, and the limitations to this praxis. Dr. Reece has published in the areas of 'Race' and Racism, Feminism, and Criminological studies and her most recent publication titled "*Carceral Redlining: White Supremacy is a Weapon of Mass Incarceration for Indigenous and Black Peoples in Canada*" (2020) was published by the Yellowhead Institute.

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