

## 4 The time of a life

### Ethics and cancer care in the case of a young First Nations girl

*Stuart J. Murray and Tad Lemieux*

Is it possible that despite our inventions and progress, despite our culture, religion and knowledge of the world, we have remained on the surface of life?

(Rilke 2009, 15)

#### **Introduction**

In May 2014, near Brantford, Ontario in the Mississauga-Ojibwe reserve of New Credit First Nation, 11-year-old Makayla Sault, living with acute lymphoblastic leukemia, reported that she witnessed the figure of Jesus Christ enter her room accompanied by two angels, and, with hands outstretched, assure her that she was healed of her illness. Makayla had, until this time, been undergoing a series of chemotherapy treatments on the advice of her oncologists at the McMaster Children's Hospital in Hamilton, Ontario. In a videotaped letter, posted online on May 13, 2014, Makayla read the following in the presence of her Band Council:

I know that what I have can kill me, but I don't want to die in a hospital . . . When Jesus came into my room, [he] told me not to be afraid. So if I live, or if I die, I am not afraid . . . Jesus told me that I am healed, so it doesn't matter what anybody says. God, the Creator, has the final say over my life.

(Ojibwe Child Refuses Chemo 2014)

And with that, Makayla withdrew from what her physicians deemed to be potentially lifesaving treatment in favor of pursuing Ongwehowe Onongwatri:yo, Indigenous medical therapies administered by a traditional healer on the Six Nations.

This chapter offers a critical analysis of the colliding ethical claims to life and to care in the case of Makayla Sault within the frame of neoliberal biomedicine and its temporalities of governance. Reading the widespread media coverage, we suggest that Makayla's refusal to consent to further biomedical therapies may be read, among other things, as a counter-hegemonic threat to the neoliberal management of *bios*, a threat that effectively destabilizes the biomedical deferral of mortality, its discourse eliding the proximity of death to life, and the extent of its authority over the time and treatment of human bodies. It is not simply

that religious faith or cultural beliefs clash here with our widespread faith in biomedicine, as it might first appear. Indeed, these discourses themselves are imbricated in (neo)colonial projects at the intersection of religion, traditional Aboriginal cultures, biomedicine, capital, law, and the politics of self-determination and sovereignty. After all, it was often in the name of Jesus that scores of Aboriginal children were stolen from their families and institutionalized by colonizing forces—the same Jesus invoked by Makayla in her refusal to submit to biomedical institutions and treatments, which for some, surely share in that colonial legacy.

Claims to and, frequently, on behalf of the body in question raise ethical challenges for conventional notions of autonomy and informed consent, including an individual's "capacity" to refuse treatment, and the right to live, and to die, in one's own time and place. In what follows, we ourselves refuse to pass judgment on the case of Makayla Sault, but, employing her case as a site of contestation, consider rather the manner in which neoliberal biomedicine relies on the fiction of an ethical "capacity" imagined to be the inalienable property of the reasonable individual, and all that such "reasonability" entails, when faced with a diagnosis of cancer. Our reading advances a provisional concept of ethical relationality that does not seek recourse in increasingly neoliberal instantiations of autonomy, reasonability, and consent; nor does it accept "cancer" as an objective reality grasped best—or only—by biomedical rationality. As S. Lochlann Jain (2013, 4) argues, cancer is "[a]nything *but* an objective thing, cancer can be better understood as a set of relationships—economic, sentimental, medical, personal, ethical, institutional, statistical." We seek, then, to surface some of the ways that Makayla's refusal problematizes such relationships. Following Jain (2007), this chapter gestures instead toward an elegiac politics of the living and a conception of voice that, in speaking, refuses to fetishize (neo)liberal individualism and the biomedical "untimeliness" of an individual's death. It is within the context of an elegiac ethics, we argue, that a robust understanding of care might emerge: one that exceeds the suasion and "capacity" of ethical codes and guidelines to suggest instead a care that must wrestle with claims that are ultimately indeterminable and temporally ambiguous. Finally, in refusing to pass judgment on the case of Makayla Sault, we stand in opposition to the many commentators who have passed judgment on her, her family, and her community: rather, we question the conditions and coordinates under which it is deemed permissible, if not morally requisite, to speak for or on behalf of others whose voices we might prefer not to hear.

### **"Capacity" and consent: the backlash against Makayla's refusal**

Makayla's public refusal elicited a biopolitical backlash from her physicians and the mainstream news media. What followed was a series of institutional threats to force biomedical treatment on Makayla, echoed and rebounded by the subtle, though sometimes quite explicit, scorn and derision of her refusal. A series of interviews with Makayla and her family were held to determine the nature of the

refusal to consent to medical treatment, where it was claimed by the family that one particular oncologist ridiculed the efficacy of Indigenous medicines by calling them “100 percent ineffective,” stating that the support of such medicines should result in prison sentences (Garlow 2014). The language of the Canadian Cancer Society (2014)—which refuses to employ the term “treatment” for Indigenous medicines, opting instead for “healing practices”—offers some hint of a context for these comments in its assessment of traditional Indigenous medicines, stating: “Although First Nations traditional healing practices have been valued by their people for as long as oral tradition has been alive, there is virtually no research on the effectiveness of these methods.” In this contest of refusals, Makayla’s refusal is dismissed, both by physicians and across the mainstream media, as the uninformed speech of primitive oral traditions or mere “values,” whereas the Canadian Cancer Society is authorized by the literate knowledge of advanced bioscience or “facts.” In an advanced neoliberal democracy, it is clear which worldview will hold moral sway and intervene into lives, even if its positive knowledge fails to encompass the moral value of that life as a life lived. This much remains beyond its ken.

Makayla’s medical service providers at the McMaster Children’s Hospital reported her case to the Brant Children’s Aid Society (CAS) to determine, using the language of the *Health Care Consent Act* (Government of Canada 1996), her “capacity” to consent to the refusal of continued chemotherapy treatments. On May 20, 2014, Makayla was deemed capable by the CAS and no further legal actions were taken against her and her family. Significantly, while the *Health Care Consent Act* does not specify a minimum age of consent, in Canada there is legal precedent for deeming a minor incapable to refuse medical treatment in the context of a religious claim, as in the case of Jehovah’s Witnesses, for instance, where minors have been required to undergo lifesaving blood transfusions.<sup>1</sup> In Makayla’s case, however, it appears that religious faith, while ostensibly the grounds for Makayla’s videotaped refusal, was not so much at play when authorities deemed her to be capable to make such a momentous decision. As a refusal on religious grounds, her public statement is logically inconsistent and contradictory. Moreover, both her mother and father are pastors in a Christian evangelical church, which might reasonably have raised concerns about who exactly is consenting in the refusal of treatment for this 11-year-old girl. We have no documented record of the interviews that took place between the CAS and Makayla and her family, nor do we have hard evidence of how the CAS arrived at its decision. On the surface, however, while there might be compelling reasons to reject Makayla’s “capacity” because she may have been unduly influenced by her parents’ religious faith, denying her capacity on these grounds would have obligated the state to intervene, and thus would have raised the further question of whether the state has the right or duty to remove an Indigenous girl from her territory, and to force treatment upon her. In this reading, Makayla’s Indigeneity becomes the salient locus of capacity—or more precisely, the locus of the CAS’s refusal to refuse to attribute capacity to Makayla. Rightly or wrongly, unwilling to enter into a contest over the rights of Indigenous persons of any age, the CAS

must by default deem Makayla to be capable to refuse treatment, however incapable—legally or ethically—she may be.

Some may argue that the CAS acted surreptitiously but in good faith to tacitly honor a First Nation's sovereign claim, but something else is taking place in this ruling, something slightly less magnanimous. In effect, the CAS anxiously produced and bestowed individual "capacity" when it made its ruling. Remaining silent on the question of Indigeneity, this administrative–legal body, operating on the authority of the state, refuses to give voice to an Indigenous claim, while nonetheless assuming the sovereign power to grant or withhold the very "capacity" by which any such claim could be recognized in the first place: You have the right to make this claim, so to speak, as long as we first bestow upon you this right, and accord you this standing in the eyes of the law. In other words, your claim is a claim always and only by virtue of our prior act of recognition, and remains ours to bestow or withhold. You are beholden to us.

Indeed, if such a power lies with the state, then the very notion of individual "capacity," in its legal valences, relies on the productive fiction of an autonomous, reasonable, (neo)liberal subject—a fiction that remains the sole privilege and purview of state discourse and power. This is true no matter the age of the claimant, but becomes all the more conspicuous in the case of an 11-year-old. If the grounds for "capacity" in Makayla's case are weak, as they arguably are, it might nevertheless have proved a safer bet for the CAS to deem Makayla herself to be autonomous, reasonable, and free to decide, rather than become embroiled in a contest of community will and Indigenous sovereignty. That is, although Makayla's Indigeneity seems to have been the deciding factor in her case, (neo)liberal state institutions would undermine their own authority, and the mechanisms of that authority, if they were to admit that "capacity" belongs also—or perhaps even primordially—to a people on the basis of shared tradition, culture, or ancestral heritage. If the state embarked on such a debate, it would expose the fictional nature of individual "capacity," along with the fragile authority—and arbitrary violence—by which the state itself produces and polices individuality as an instrument of governance, if not subjugation.

The tension between the claims here becomes all the more palpable if we consider in stark terms the consequences of acknowledging that peoples—and not individuals—might be the bearers of certain rights or "capacities," particularly as these continue to be conceived and fashioned on the basis of Enlightenment Western individualism and law. The law is hamstrung, in a sense, by its own language, its own conceptual authority, and on its own founding principles, which are meant to apply universally, and yet come up against cases like Makayla's where much more than the life of an individual hangs in the balance. The United Nations *Declaration on the Rights of Indigenous Peoples*, to which Canada is a signatory, complicates the medico-legal paradigm of ethical individualism in provocative ways, and yet this document was rarely invoked in the public discussion that followed Makayla's refusal. How is the law to incorporate a UN *Declaration* (2008, Article 24.1), which states that Indigenous persons cannot be forcibly removed from their traditional territory, or the claim that they "have the right to

their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals”? Indeed, the *Declaration* states further that: “Indigenous individuals also have the right to access, without any discrimination, to [sic] all social and health services” (2008, Article 24.1). This suggests that whole peoples can be the bearers of rights, and are free to invoke a sort of capacity that does not refer to individuals, but rather problematizes this legal category as belonging to a worldview that is not and never really was universal, timeless, and True.

What the UN *Declaration* might mean in Canadian legal and ethical practice is far from clear (it is certainly not legally binding), though it was clear that trespassing upon First Nation territory to forcibly remove a young girl from her family would have been met with resistance and declarations of war from First Nations everywhere.<sup>2</sup> In an opinion column written for the *Hamilton Spectator* on May 31, 2014, Juliet Guichon, a legal scholar, along with three pediatricians of her cohort in the Faculty of Medicine at the University of Calgary, contend that “[a] young Canadian girl is being denied a good chance for a cancer cure because she is aboriginal” (Guichon et al. 2014). Arguing that Makayla is too young to consent, Guichon and her colleagues, in their characterization of the CAS’s decision, describe the uneasy tension between the community that Makayla belongs to, and the individual—here a “young Canadian,” a citizen—who is managed, statistically described, ordered, and constituted as a subject of neoliberal biomedicine and law. In an argument that is either blind or indifferent to Canada’s colonial history, they claim that it is tantamount to discrimination for our medico-legal institutions to *fail* to provide (forced) chemotherapy treatments for Makayla, and that this discrimination is an injustice, it would seem, that trumps the rights of Indigenous persons to their traditional medicines. Indigenous persons’ right to “access . . . all social and health services,” “without any discrimination,” as the UN *Declaration* puts it, is here rendered as their obligation, a responsibility rather than a right. That is, it appears for the authors that the community should be the locus of consent and capacity, as a proxy for the individual who is incapable of consent, and yet Guichon and her colleagues undermine that capacity—the community only possesses such capacity, it would seem, when it makes a decision that is concordant with the authors’ and with the medico-legal establishment they represent. In other words, in their reading the community has refused to exercise capacity, and, in its decision, has abrogated its right to make a decision, or has proven itself preternaturally incapable of doing so when it too refuses to force Makayla into treatment.

Guichon and her colleagues choose not to invoke the UN *Declaration*, turning instead to the authority of the Supreme Court of Canada, citing legal precedence for the state’s medical intervention in cases they deem analogous.<sup>3</sup> They appear to take issue with Aboriginal exceptionalism. Yet there is no mention of the many other historical “interventions,” many of them exceptionally bloody, which might, for a First Nation community, trouble the Court’s authority as belonging to a colonial tradition—indeed, a tradition in which Makayla is co-opted as a “Canadian girl” in need of biomedical salvation and legal sanctions. Nowhere do they ask:

What is the “capacity” of the law and *its* institutions in this case? Whence *its* capacity to judge, and to bind us to that judgment? And is this capacity not founded in the historical violence that consented to—when it did not altogether sanction—the abduction of Aboriginal children, and sometimes their rape, their destitution, before the law, in the name of Jesus and in the name of the state? If this is the history of its authority, the question of capacity is evacuated of meaningful content, and we are left with the enduring question of the responsibility for life and its relation to the ugly, forgotten, disavowed, history of law.

There is, of course, a “logic” to the trite claim that two wrongs do not make a right—that Makayla is being martyred, wrongly, on the altar of her community’s principles and politics, and that by denying her chemotherapy treatments we—however this “we” is constituted—add to, rather than redress, historical injustice. But this is to refuse Makayla’s claim outright, to refuse to hear it on its own terms, including the sovereign claim that is voiced in her name, and the care that is given through the community that loves and embraces her. Such a refusal does not redress historical wrongs, but reduplicates them. Could there be something positive in Makayla’s claim, something we might recognize, however vaguely, in the desire to live—and to die—in one’s own way? Could death be something other than the mere failure to continue to live, by whatever means? The law is decidedly anxious here, which is one reason why it might have reinforced Makayla’s individual capacity, bestowing and then by sleight of hand “recognizing” this capacity, rather than acknowledge the sovereign claim of her Nation. In her own way, Makayla invokes the absolute power of law when she declares, “God, the Creator, has the final say over my life” (Garlow 2014). This declaration stands in contradiction to the manner in which the law has arrogated to itself such theological power in an ostensibly secular context. The law remains unwilling to cede on the question of sovereignty over the lives of its subjects, which is its ultimate power, and a mythic violence that underwrites its authority across the spectrum of social life.

### **Biomedicine, biopolitics, and sovereign claims**

Whether Makayla’s community has the capacity to refuse treatment on her behalf, abrogates its capacity, or refuses outright the terms of “capacity” and the authority by which it is bestowed or normatively produced, performed, and policed, her community nevertheless makes a sovereign claim in her name. And while the law might bestow upon Makayla the individual capacity to refuse treatment, we suggest that it does so grudgingly, because it cannot tolerate a sovereign claim that would compete with, and threaten to undermine, its own claims to sovereign authority, universality, and force of law. The sovereign victory of the First Nation is here a silent one, operating spectrally, behind the face of a little girl whose contradictory story—she does not want to die in the hospital, yet Jesus said she is already healed, yet she will turn to Indigenous medicines—is apparently good enough for the law, good enough for the ruse of consensual personhood. Politico-legal battles converge at the site of Makayla’s body, and the wider dynamics become reductively biomedicalized in the popular imaginary: stated simply, in

reductive terms her community has failed her by failing to act in her best medical interests. And so her community has, we are led to believe, failed to exercise its capacity—its responsibility—to enact the rule and authority of biomedicine to make Makayla live, or to give her the best chance at life.

The irony is that while the CAS deemed Makayla to be capable of refusal, within a neoliberal biomedico-legal context her refusal of treatment is practically illegible, signaling a de facto *failure* of capacity—for no “capable” person, on its terms, would refuse life or the best chance at life. Within a biomedical context, that is, such a refusal is seen as irrational, issuing from someone who demonstrably cannot make the right choice, and who abrogates the right to belong, recognizably, and to make a claim that could be honored. The sovereign claim of the First Nation, then, is an affront to the consuming logics of biomedicine, which in the wider culture has been naturalized and normalized as commonsense truth. In Foucault’s (2003a, 202) terms, we characterize biomedicine as one aspect of biopolitical state power: biopolitics is “the endeavor, begun in the eighteenth century, to rationalize the problems presented to governmental practice by the phenomena characteristic of a group of living human beings constituted as a population: health, sanitation, birthrate, longevity, race.” Within biopolitics, medicine and law become rationalizing tools for the political organization, regulation, and management of life itself. Today, moreover, we must understand biopolitics in a neoliberal vein, with global proportions and diverse modalities, which is why cancer is not an object but more than ever a complex set of relations. Foucault’s (2003b, 241) early formulation of biopolitics as “the power to ‘make’ live and ‘let’ die” can no longer be understood outside a vast and anonymous global network. It operates to “make live” through technologies, mechanisms, efficiencies, forecasts, statistical estimates, and risk management. It defines, regulates, counts, exposes, and encloses human life on our planet, from Attawapiskat to Athens, from Davos to Darfur: information economies, surveillance, Big Pharma, clean drinking water, famine, HIV, cloning, genomics, and the cancer industry, to name just a few—a diffuse “agency,” an ideology, that is unlocalized and operates through a plethora of loosely connected sites: medical, juridical, social, political, cultural. Through burgeoning governmental and biomedical technologies, the individual’s life now counts first as a biological member of the state’s population, one biopolitical entity among a mass of others, or, as Foucault (2003b, 246–7) sums up, “man-as-species.” Effectively, the “individual” is displaced and becomes “regularized” by “a technology in which bodies are replaced by general biological processes” (2003b, 249). Here, relations of power, and historical “interventions” of all kinds, are invisible behind the biomedical “fact” of cancer. Is it possible, as Rilke suggests, that we remain on the surface of life?

The cancer diagnosis constellates around the hegemonic narrative of empirical truth and its realities, where the body is made to live, and meant to live, by whatever means offered by the rules and technologies of biomedical logics. The often-silenced counter-narratives of life and death, of health and healing, are and must be staged within the scope of a past long left behind and disproven. In the near borderless and faceless mechanisms of neoliberal biopolitics is produced, as a

necessary condition of its operation, a trajectory defining a particular form of life and the various expressions, or symptoms, which determine its character as such. Not all lives are liveable. Life itself becomes, both in context and content, the concept defined for and through neoliberal biomedicine and the measure through which bodies are made to live. Thus, the project of neoliberalism is, in part, the task and management of pre-empting death and death's presence-in-life, foreclosing upon any "decision" that is not made in the name of "life itself." Life, as manufactured and managed, enforced across a population in part by the common-sense principles coded into the (neo)liberal subject, operates as an object of futurity whose meanings are constantly deferred by biomedical progress and treatments. Cancer "becomes" the present, but biotechnology and its concurrent narratives of life constantly work to project this idea of living into the future and death into the underside of the abstract silence of the percentage point promising that deferred, healthy, life. In this capacity, neoliberalism operates outside of the present and out onto a belated future that becomes both predictively predetermined and, yet, never operationally present. It relies on statistical paradigms and predictive rationalities projected into the realm of potentiality, the determinacy of the future, to dismiss or defend against the proximity of death in the narrative of biomedical and biotechnological progress.

"Death," within a biopolitical frame, must here be understood as distinct from "letting die." It is as if death does not come for those who are made to live: and those we "let die" do so, as it were, of their own accord, due to their constitutive biological failures, weaknesses, abrogations. These deaths, if we can acknowledge them *as* deaths, are disavowed, dismissed as lives that did not quite count as life, that did not make it, that were constitutively unlivable. Foucault suggests that in the biopolitical State, "making live" and "letting die" are intimately connected, each the obverse of the other—"letting die" as the consequence, and the condition, of "making live," much as we might callously see the deaths produced by pharmaceutical trials as the "collateral damage" or "negative externalities" of making live. In a controversial lecture, Foucault (2003b, 254) argues that the power to "let die" occurs primarily as an inscription of racism into the mechanisms of its power:

Racism makes it possible to establish a relationship between my life and the death of the other that is not a military or warlike . . . but a biological type relationship . . . [T]he death of the other, the death of the bad race [is] something that will make life in general healthier: healthier and purer.

Faced with the refusal to "make" Makayla live, the medico-legal discourse—naturalized and popularized in the mainstream press—props up the health of neoliberal biopolitical ideology against the "impurities" of other ways of understanding life, health, medicine, and death. And in doing so, the ontology of biomedicine is posited as a purity of progressive thought, a causal line out from the murkiness of the primitive past and into the future informed by an ever-increasing biotechnological mastery over the terms of mortality. These kinds of impurities are "allowed" to die—though always in the name of proliferating a certain form

of life—and with them, their own frames, their own narratives, their own concepts of life, the times of their lives, all while subject to a reinforcing ridicule acting the part of the ethical caregiver who has been refused the capacity to intervene, refused the capacity to defend the purities of dominant ideologies by enforcing the law of the land. The White Man’s burden. If Makayla dies from lack of biomedical treatment, she will have been “allowed” to die, almost passively—she will not have been killed, but will have died due to the constitutive failure of her Indigenous community to exercise its moral capacity to choose life, and to make her live, in the terms and through the technologies that are generously proffered. This, in any case, is the implicit narrative.

Our argument, therefore, hopes to suspend for a moment, to break free from, the constrictive onto-logic of neoliberal biopolitics, which has been normatively inscribed today as common sense to the population it authorizes and proliferates. Our purpose is to explore the ethical valences within Makayla’s refusal of the biopolitical program, and to expose the reductive constraints that define ethical care in the era of neoliberal biomedicine. To do so is once again to expose as well the fragility of our own implicit narratives, borne by a faith in the efficacy and causal circuitry of biomedicine, and the fractiousness of the perverse narratives of biopolitical truth and biotechnological progress, here operating hand-in-hand with the legal and administrative bodies that render judgments on capacity and care. Makayla’s story presents one challenge to the trajectory and determination of the neoliberal conceptualization of life, a gaunt choreography acted out at the anxious limits of its reach, and the practiced course extended out and within the interconnected web of private and public media used to shore up the rule of its laws, logics, and narratives—our way of life.

### **Biomedicine and the “untimeliness” of death**

Within the subtle bio-discourses advanced by neoliberal biopolitics, the time of “life itself” is a managed, mandated, and moralizing story—a linear-sequential time dictating the boundary of not-being and illness. The diagnosis of Makayla’s illness, her prognosis, and the perceived statistical proximity of her death, highlights the contours of this particularized time. Indeed, her refusal to accept the numerical borders of livingness offered by chemotherapy, the abstract statistical promise of belatedness, a continued and determined trajectory of living, animates the call for biomedical intervention precisely because the presence of her illness in the time of her life is understood as arriving too soon: her illness, but worse, the present possibility of her death, demands to be recognized as untimely within the scope of a particular narrative of life. The rhetorical posturing of the “untimely” can be understood as concurrent with the ahistorical staging of modernity—the un-timely—that in turn informs the linear-progress narrative of biomedicalization and biotechnology toward its fervent campaign on history, truth, and death. But the untimely is more “present” as a determination of a life lived in particular codes of biomedical time. Here, moments of “the untimely” are punctuated by those medical circumstances deemed premature, too spontaneous, a complication

of the present rather than a determination of possibility for the future, outside of the determined arc of biomedical suitability, probability, or statistical predictability. An ethics of care, we wish to suggest, manifests against, or despite, the biopolitical paradigm that reflects this temporization of “life itself” defined according to the statistical analysis of populations, risk surveillance, and the like, opening instead toward the otherness of timeframes or life-times outside this framing.

In a letter to Makayla published in the *Globe and Mail* from Heather Cleland (2014), a Toronto-based writer, Cleland recounts her own experience as a young woman battling with cancer. Cleland affirms the virtues of chemotherapy and the other drugs required to manage its symptoms, despite their negative effects on her body or the discomfort of then-present experience, but instead as a proposition of hindsight—a determination made from the future about her past self and now to Makayla herself. Without chemotherapy, writes Cleland, “I wouldn’t have finished school. I wouldn’t have spent nine whole months travelling around the world. I wouldn’t have gotten my master’s degree . . . Chemotherapy was the only reason I was able to do all those things” (Cleland 2014). Without chemotherapy, Cleland suggests, Makayla will not live to go to university, to travel, to pursue relationships, and to live a full life, as Cleland imagines it. We are to recognize that Makayla’s death will be an untimely one: a young woman robbed of life “too soon,” whose childish fears of bodily discomfort and, disturbingly, whose cultural identity are keeping her from the future that Cleland writes from, here held out as a possible, even probable, redemptive, time “to come”—uttered with all the messianism that so often accompanies the salvific promises of biomedicine and its speech acts. The biomedical determination of life’s futures, the will to “make live,” is the condition of the untimeliness of death’s proximity in the present, and a component of how long one should live, statistically, how and when illness should manifest in the living body (ideally, never), and how biomedicine and sometimes law should intervene into that proximity. But how can we know for certain the contours of the untimely in its proximity to the case of Makayla Sault, and how the design of this temporal aspect of biopolitical “life” represents itself on the frontiers of an ontological struggle for meaning, when the specter of the residential school, of the so-called “1960’s scoop,” of the decaying and forgotten infrastructure of the reserve, directly faces the power actively sketching the meaning of “life itself”? What sort of imaginable future announces itself from these ruins?

In the mainstream media frenzy that followed Makayla’s refusal, most of it studiously silent on these colonial histories, we can read a string of binaries that spring from these temporizing constitutions and that lend flesh to the meaning of our biopolitical lives: primitive/modern, faith/knowledge, religion/science, value/fact. Binaries such as these suggest a natural progression toward a life lived within (and without) certain frames, until certain times, under supervised conditions, and managed by entrepreneurial subjects who “freely” employ a cadre of service providers and experts, medical and otherwise, for their own betterment, vitality, self-actualization. Thus, one’s life-time is encoded in a broader story of progress against the “violence” of death to the human *bios*, written into the linear-processual narrative of biomedicine and employed as a framing of life itself inside

the litany of seductive tropes that characterize neoliberal biopolitics. These form the privileged narratives of progress that delimit the possibilities for narratives otherwise, those ways of knowing and interacting with the world that are incompatible with the proliferating and performative regimes of evidence-based practice, randomized controlled trials, techno-scientific advancements, and disease and risk surveillance. What it means to live, to regard the time of one's life, outside of these frames becomes not only an untenable but an unthinkable proposition, indeed, insufferable, intolerable, even cruel.

### **Conclusion: toward an elegiac time of life**

And yet, this unthinkable becomes the time of one's life in the all too real proximity of death, where the linearity of time itself becomes insufferable, intolerable, cruel:

When Mary found that her cancer *had* spread (had, indeed, been spreading), her health status retroactively shifted. *I am alive. No, you are . . .* In one swift motion, the cancer prognosis detonates time, which scatters like so many glass shards.

(Jain 2013, 28)

This is the subjective temporality of cancer, of detonated and scattered time: past tense, past perfect, present, and future enter into catachresis. While the cancer prognosis detonates the time of one's life, the treatment imposes its own time, consoling us, perhaps, with the seemingly objective temporality of statistics, the biomedical time of cancer, a series of moments in waiting rooms and on gurneys, painful tests and biopsies, X-rays and CT scans, pathology reports, the scheduled stings of the infusion needle, regimes of medication, hospital parking lots, management of food and drink intake, the anxious days and weeks of waiting for test results, chemo "daycare" clinics, wig fittings, visits from timid well-wishers, etc., held together by the promise to defer the certainty of mortality, and the ways these each and all affect the experience of other times and places, retrospectively and prospectively. The purported certainty of statistical time—the predictive rationality of neoliberalism, statistical biomedicine, and anatomopathology—does not and cannot map onto the time of a life. "*I am alive. No, you are . . .*" Alive, yes, living, a statement of fact that is countered at once: No, you are . . . Not quite dead, not yet, but dying, surely, whatever that might mean. But the prognosis radicalizes this death-in-life, bringing death into intimate proximity such that the distinction between life and death, operating so commonly as binary terms—and imbricated, too, with the binaries above—opens instead onto what Jain calls "living in prognosis," or prognostic time.

Here is a time catered to the future, the possibility, necessity, of being unto, of continuing elsewhere in time, and by virtue of the ordered imagination of one trajectory of livingness. But so too does this time fetishize a magnitude of the past, demanding the reality of untimeliness by crashing the time of a life offered

as obvious and deserved, earned by biotechnological mastery and also disfigured by it. “*No, you are . . .*” Not supposed to die, *yet . . .* An unfocused barrier between the adverbial and the conjunctive forms appears in this disintegrated temporization of prognosis, where the “*yet . . .*” operates as both the deferral of the present into the future and its negative horizon, manifest from the statistical prediction of being in a future, what lies, or does not lie, just around the numbers, and what it means in the present and for the past. A narrative of life not only interrupted but deceived, and within which the prognosis promises a series of renewed deceptions for the time of one’s life, one’s future, one’s death.

We may also perceive in this constrictive biomedical time, metaphorically, but maybe also literally, a colonial time: of the colonizers and their order, the time of the Metropole, of the processual and hegemonic regime of the clock and the schedule and the assembly line, the time of law and the self-authorizing power of its rule over subjects, the seemingly timeless mechanisms and developments of modernity, deceptive yet seductive, and the averted cultural and social channels of lives lived otherwise. In this, the body of a young girl is colonized in all senses, not just by cancer but by the consumptive impositions of biomedicine, religion, history, law, labor, social services, living within the onto-logics of their timeframes, and their suggested, demanded, order of and over her life. The battle for Makayla’s body is the battle to continuously define life inside of the complex network of temporalities of governance as the “when” of a life, and the “who” that is allowed to die to help these definitions flourish in time.

Risking the charge of naïveté, or worse, a neoprimitivist or romanticized characterization of Aboriginal peoples, we have sought in Makayla’s story to honor the time of her life as a refusal of the colonizing forces of biopolitical neoliberal time. We have tried not to essentialize her identity or to judge how her decision is voiced but to problematize the myriad responses to this refusal and to begin to set them into wider social, historical, and political contexts. Within such a presentation, Makayla’s story serves as the occasion for a claim about the manner in which neoliberal biopolitics and the medico-legal and juridical complex seize upon and mobilize a particular form of “life itself.” We adapt Jain’s notion of an “elegiac politics” vis-à-vis cancer to propose an elegiac time as the time of one’s life—a time that would refuse the temporizations of biomedicine, and open instead onto, or perhaps more tellingly, from, the time of a life lived and spoken in the intimate proximity of death. Traditionally, elegies are melancholic laments for the dead, but they intrude into life, are sung or spoken by the living, and acknowledge that our living work of mourning, our grief, is not done. They signal the continued presence, the lives, of those we have loved and lost, who we harbor deep within us, unwilling or unable to let go (see Freud 1957, 237–58). This continued presence is in part political because it honors the dead in the lives of the living, and affirms their importance for the *polis*, the community. Speaking of an elegiac politics of cancer, Jain (2007, 89) writes:

An elegiac politics argues for pushing the private face of cancer cultures—grief, anger, death, and loss into the public cultures of cancer—perhaps even

if only alongside of LiveStrong, or sipping, driving, and walking for the cure—with the recognition of the enormous economic profits and gains that parallel these losses.

In this respect, this chapter hopes to perform an elegiac politics, and to imagine how this might be brought into the present, as a life lived, despite the counterfactual futures of neoliberal biomedicine. It asks us to hold together, for a moment, claims that are ultimately indeterminable and times that are temporally ambiguous, where the categories of public and private enter into catachresis, and myriad intersecting and conflicting claims are brought to light.

Where the elegy denotes the solemn but oftentimes equally joyful work of loss and mourning and remembering, it does so by holding onto the ambivalence of death-in-life, and narrating the time of a life, singing it, speaking it, celebrating it. As Jain (2013, 223) puts it more recently in terms that are disarmingly folksy yet insightful, “Cancer is both okay—it has to be okay, because ultimately, for people who are dying, death has to be okay—and not okay.” Of course, under the regime of neoliberal biomedicine, death is not “okay,” nor is it “okay” to refuse potentially life-saving treatment. “It is not okay,” Jain writes,

that our languages are deceitful, that people with cancer are blamed or shamed or promised that they will survive or asked to disguise themselves . . . An elegiac politics . . . helps make this contradiction (okay, but not okay) not only legible, but livable and dieable.

(2013, 223)

Jain seeks to “retrieve the individual” from his or her obliteration into statistics and datasets and probabilities—“from the aggregated thinking that contemporary cancer knowledge forces us into” (2013, 223)—to live a life elegiacally, we might say, livable and dieable both for those patients who are compliant, but also for those “bad” patients (see Steinberg 2017, this volume), individuals like Makayla, who the regime renders unrecognizable, ultimately responsible, and in the final moments, perhaps, unable to be grieved, mourned, elegized. Our gesture here, most emphatically, is not to return to (neo)liberal conceptions of the autonomous or consensual subject—the sovereign reign of the individual, nor is it to locate an ethics in such medico-legal subjectivation. Rather, it suggests an elegiac ethics in the fraught, ongoing narration of a life lived, in the often disharmonious relationality of elegiac voices, and to recognize that this is a song sung, as it were, by the living and the dead. It is here, then, that (neo)liberal conceptions of “sovereignty” clash with claims to popular sovereignty, where a claim might emerge from and on behalf of a people—the temporality of which exceeds the individual life—to give voice to others, which might well include our ancestors, founding fathers or mothers.

The temporal value of an elegiac life is ambivalent. Ethically, it lacks the clarity of focus that statistical prognosis purports to offer, and approaches hegemonic temporalities on a day-to-day basis, in the act of loving and being loved, in the

experiential, intersubjective moments of living, in dreams and visions, within and across a community or communities of reception, within and across clock-time. The time of a life approaches these figures of technological time, colonial time, biomedical time and tries to make sense of itself despite and in the face of them, interceding, often failing, and yet celebrating the contours not offered by the fixed relationality of *bios* management, the determined future of the statistic, the story already told in numbers and charts and needles and yet unread and unfelt in the body of one afflicted by an illness. “[T]ime in elegy wraps itself around the subjective life *and* death of each of us who passes through the timeless grammar and promise of cure, compensation, and the captured youth of a photograph” (Jain 2007, 90). That is, the time of an elegiac life unfolds in an expansive array of lived moments, open to the relationality of other ways of living life, of approaching and seeing death in oneself and others, of understanding and disclosing, and in doing so encounters fixity with another kind of seeing to the abstract codes of vitality, health, life, death, the present, and the future. Death is recollected in life as possibility, a confirming proximity not simply denied or refused its purchase, but instead granted as a contour of an open and relational narrative of life lived with and alongside others, living and dead.

Is it possible that Makayla’s refusal begins to give voice to ineffable terms for the time of a life, and points to the fractures in conceptualization for life defined and written within our neoliberal biopolitical frames? Indeed, Makayla’s story begs the question of a life lived, understood, and pursued otherwise, a narrative of history that must lead into an indeterminate future, where the path of a life is not defined by the aggressive silencing of death, nor the orderly and scheduled time of being. What would an ethics of care look or sound like if it spoke in the presence of an elegiac time of life? It is at best reductive for an ethics of care to imagine and to treat life within the scope of biomedical, colonial, neoliberal, and technological time alone—a life that does not act in other times, experience other times, or know them, but trades relentlessly in counterfactuals. Rather, ethical care must wrestle with the ineffable grammar of the time of a life, to try to elegize the times of living asserted by and woven into the relationality of community, the shared declaration and affirmation of times to live, to die, to know them otherwise, and as one’s own to tell and be told.

### **Postscript**

On January 19, 2015, Makayla Sault, at home in her bed, suffered a fatal stroke. In the time that followed the decision by the Brant CAS to bestow capacity upon Makayla to refuse continued chemotherapy treatments in May 2014, the attacks and accusations against her and her community, the appeals for her life, shifted to a similar case of another 11-year-old First Nations girl—only referred to as J.J. due to a publication ban—with lymphoblastic leukemia who also decided to refuse treatment. J.J., from Grand River First Nation, nearby to the New Credit First Nation, was also being treated at the McMaster Children’s Hospital. As in Makayla’s case, the hospital contacted the Brant Family and Children’s Services

(BFCS), which services Grand River Reserve, following J.J.'s refusal to continue treatment in August 2014. And, as in Makayla's case, BFCS found that J.J. was not a child in need of protection. The McMaster Children's Hospital then took the extra step in the wake of that decision to bring the BFCS to court, hoping to force them to remove J.J. from her family and to impose the chemotherapy treatments that would save her life—at least, within the abstract futurity and almost-certainty of the ninetieth percentile. In a November 2014 decision, Justice Gethin Edward of the Ontario Court of the Justice, in a landmark ruling, not only found that J.J. would not be removed from her family, but that the “decision to pursue traditional medicine” is her “aboriginal right . . . a right [that] cannot be qualified as a right only if it is proven to work by employing the Western medical paradigm.”<sup>4</sup>

The implications of this ruling, and the story that it attends, far exceed the borders of this postscript. What, then, might we hope to say here—with, or through, Makayla's death? Certainly, Makayla's story—her decision, her life, her death—are in constant proximity to Justice Edward's ruling, J.J.'s decision, and in the continued backlash from popular media, commentators, and many physicians. When the news broke that Makayla had died, many such commentators responded by suggesting that her death “needn't have happened” (Mehta 2015), that she “should not have” (Wiens 2015) or did not have to die. And while these, and other, proclamations about her life in the popular media are certainly related to the so-called untimeliness of her death, Makayla's death is also illegible, unnecessary, because it was *preventable*. We might ask: What makes a death preventable? What constitutes a life lived in the service of the prevention of death? And if Makayla's death had instead occurred despite chemotherapy treatments, would her life have been lived in the time of a life that prevents death?

Such a life, we might say, in the bio-discourses of neoliberal biopolitics, is imagined, recognized, to always already exist in a world where death is displaced—disavowed somewhere among the preventable, the percentage point, the outlook. Posthumously, these biomedical discourses still attempt to prevent Makayla's death by *presenting* her life, statistically—imagining a preventative living for Indigenous children in the shadow of a misguided court decision, the life-time in the care of *praevenire*, the before-to-come. Biomedical treatment, then, always prevents her death (even when it cannot) by preventing the presence of death in discourse, in life, in care. It is therefore not surprising that news of Makayla's death has been used to shore up the Truth of biomedical care and its narratives of progress against J.J., Justice Edward's decision in November 2014, and Indigenous rights gone “off the rails.” Makayla was “allowed” to die, so say numerous commentators in the popular media, and “we” granted this allowance by not fighting hard enough against families, peoples, who, in Kelly McParland's words (2014), will not step “temporarily outside their traditional heritage.” The outside of this heritage is, naturally, the future: the future of medicine, the “progress” of care, the imagined healthy life of the body of the cancer patient saved by chemotherapy treatments. The burden, the “disgrace,” that this allowance casts on those who would prevent Makayla's death, retrospectively, to make her

live even in death, constitutes the necessary evidence for refusing the right of those communities and peoples who, prospectively, will not properly take up the responsibility of life.

Juliet Guichon (see Blackwell 2015), in conversation with the *National Post*, argued that this case suggests “a different standard” of care for Aboriginal and non-Aboriginal children. On the one hand, a dead child who “could have lived,” and another 11-year-old Indigenous girl with the same fate; on the other hand, citizens, Canadians, to recall the appeal Guichon and her colleagues made for Makayla’s life in May 2014, who are safe along the path tread by the progress of medical science and care. “The trail [Makayla] blazed,” wrote Guichon, was, rather, only “to her own death” (Guichon et al. 2014). Of course, death here is again imagined simply as Makayla’s inability to live by the terms recognized and imposed by biomedical care, her incapacity as an individual to make the “right” choice. In Guichon’s terms, it seems, the refusal to consent to biomedical treatment is simply the long march to primordial and savage history, the oblivion of the past and death. Such a trail has been blazed by others, forgotten others, left behind and propped up as examples in the biopolitical imaginary. The future here has already been decided, and in Guichon’s terms, Makayla’s march was backwards, not forwards, into death. Understood as such, Makayla’s death is invisible, reduced to the future she was never allowed to live, to the disavowed past, and serving only to reify the truth that J.J. will die an untimely, yes, but also timeless death if she, and others, continue on that path.

A complicated temporality again converges on Makayla’s body, where the *was-preventable* of her death (and by implication, J.J.’s life) meets the time of her life. While bio-discourses make Makayla live, over and over, by engaging in the theater of her imagined future, performing her life because her death is untranslatable, J.J.’s decision to live otherwise continues to challenge these moralizing narratives. As we have argued, Makayla’s story, among other things, potentially offers us the means with which to wrestle with the indeterminacy of the future, the relationality of community, of illness, health, the proximity of death, and the grammar of lived moments that constitute the time of a life. While the discourses of neoliberal biopolitics can do no more than to make Makayla live in spite of death, her community, and other communities, might remember and share how the time of her life affirmed a different kind of time to live and to die: “I think she will be remembered partly as a trailblazer,” said Chief Bryan LaForme of New Credit First Nation (cited in Mehta 2015). “She set the course for a court action that worked in the favour of First Nations across the country” (cited in Mehta 2015). In this, perhaps we can ask whether or not it is possible that Makayla’s story tells of the care that other, indeterminable, ways of living and dying open up toward a future, and speak against the silencing of death-in-life for and with others, living and dead.

## Notes

- 1 In the 2009 Supreme Court of Canada case, *A.C. v. Manitoba (Director of Child and Family Services)*, the Court ordered that a 15-year-old Jehovah’s Witness be forced to undergo lifesaving blood transfusions against her will. For children under 16 years of

- age, there is a judgment of “maturity”; the greater the significance of the decision, the more the state has a right to intervene in this judgment. See *A.C. v. Manitoba* 2009 SCC 30.
- 2 Dawn Martin-Hill, chair of Indigenous Studies at McMaster University, offered an ominous warning of such potential, urging against provoking the “wrath” of the “warrior societies” intent on guarding Makayla from forced treatment and removal. See Pecoskie (2014).
  - 3 Although Guichon and her colleagues do not mention it by name, they refer to the Supreme Court case cited in Note 1 above.
  - 4 See Kelly Grant (2014).

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