Healing Generational Trauma in Aboriginal Canadians

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ABSTRACT

On January 19, 2015, Makayla Sault, an 11 year old Aboriginal girl, died of leukemia.[1] Although her physicians gave her a 75% cure rate with treatment, she and her family refused chemotherapy in favor of pursuing alternative therapies. Earlier in 2014, she completed 11 weeks of chemotherapy but decided to withdraw early. Because untreated leukemia is a fatal diagnosis, the medical team tried to convince Makayla and her family to proceed with the treatment and an ethics consult was obtained to support communication. Discussions broke down however and Makayla left hospital. Many Canadians were angered by what they perceived as the justice system failing to intervene to save Makayla's life. What is lacking in much of the discussion about cultural safety locally and internationally is meaningful data collection and research around how effective the above interventions are.[27,28] Key to the concept of cultural safety is that quality and safety are judged by Aboriginal patients, not by health care providers or institutions

Keywords: cancer, case study, leukemia, chemotherapy, traditional medicine

CASE INTRODUCTION: MAKAYLA'S STORY

On January 19, 2015, Makayla Sault, an 11 year old Aboriginal girl, died of leukemia.[1] Although her physicians gave her a 75% cure rate with treatment, she and her family refused chemotherapy in favor of pursuing alternative therapies. Earlier in 2014, she completed 11 weeks of chemotherapy but decided to withdraw early. Makayla informed her doctors that, "I am writing this letter to tell you that this chemo is killing my body and I cannot take it anymore."

Because untreated leukemia is a fatal diagnosis, the medical team tried to convince Makayla and her family to proceed with the treatment and an ethics consult was obtained to support communication. Discussions broke down however and Makayla left hospital. Her physicians pursued the matter further through the local Children's Aid Society, who declined to apprehend Makayla and force her into treatment stating, "For us to take her away, to apprehend and place her in a home with strangers…when she's very, very ill — I can't see how that would be helpful".[1]

Many Canadians were angered by what they perceived as the justice system failing to intervene to save Makayla's life. Did Makayla die simply because she was Aboriginal? Others supported the Sault's decision to forgo Western medical paternalism, in favor of traditional Aboriginal medicine practices and a right to self-determination. Regardless of one's position, Mikayla's story resonates with the

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lived experience of many Aboriginal Canadians who suffer inferior health outcomes and face ongoing challenges reconciling their historical cultural narrative with that of the West.

II. DISCUSSION

A. Cultural Safety as Bioethical Framework

This paper will use a cultural safety framework as a bioethical tool to understand how Western medical institutions and practitioners contribute to broken trust for Aboriginal patients like Makayla. Cultural safety is a concept originating in New Zealand for the Maori people, and differs from other concepts like cultural humility, competency and awareness.[2] Cultural safety requires a thorough analysis of the social and historical contexts of health and health inequities. It does not focus on understanding "indigenous culture", or specific belief systems. The cultural safety approach seeks to determine the roots of social injustice, and how imbalances in power, such as in the relationship between physician and patient, shape health care experiences. It demands that safety be evaluated and judged by those experiencing care, and not those providing it.[3]

Through a cultural safety bioethical model, current and future strategies aimed at redressing health inequalities must first start with a self-reflective process on the part of the physician and health care organization. Following this, careful educational, research and policy interventions can be constructed, in concert with Aboriginal stakeholders. Although deep consideration of solutions is necessary at all levels of the health care continuum, this paper will focus primarily on the individual interactions that Aboriginal patients experience with health care providers and within health care institutions, and not specifically on governmental policy, judicial, and social reform.

B. Current inequities in social determinants of health and health care outcomes

Aboriginal Canadians continue to experience ill health and inferior life expectancy compared to the rest of Canadian society.[4] For example, the lifespan of an Inuit man in Nunavik is 15.8 years less than the lifespan of a man in Vancouver, British Columbia.[5] Aboriginal individuals are much more likely to die young from violence or trauma, and are more likely to suffer from preventable conditions like diabetes, heart disease and tuberculosis.[6] Addictions and mental health disorders are highly prevalent in Aboriginal communities.[7] In contrast, Canadians on the whole enjoy excellent health compared to the rest of the world and take pride in Canada's universal health care system and strong social safety net, founded on the principles of equality and justice. So why do health inequities continue to exist for Aboriginals?

Disparities in basic social determinants of health, including lack of access to clean water, affordable and healthy food, and healthcare in the remote regions where Aboriginals often reside explain much of their poor health.[8] To illustrate, in July 2017 there were 92 advisories for unsafe drinking water in Aboriginal communities.[9] The Canadian senate described current health conditions among Aboriginal Canadians as a "national disgrace".[10] Certainly, recent governmental efforts through the Truth and Reconciliation Committee (TRC),[11] aimed at closing socioeconomic disparities, as well as planned judicial reforms, will play a role in addressing wrongs, but this discussion is beyond the scope of this paper. Instead, let us look to the past through a cultural safety lens to better understand the historical

struggles that have set the stage for Aboriginal Canadians' mistrust of Western health care practitioners and institutions today.

C. Broken Trust: Colonial Legacy of Trauma

The most damaging tool of colonialism, perpetrated by white settlers on Canada's original Aboriginal inhabitants, is often considered to be the residential school system. More than 150,000 Aboriginal children attended these church run schools between the years of 1870 and the 1990s when they were finally closed.[12] Taken by coercion or force from their homes, children were placed in these schools for the sole purpose of "aggressively civilizing" them, or to "kill the Indian in the child." Severely underfunded and poorly staffed, these schools became synonymous with malnourishment and disease, with over 6000 children dying in care, and many more sent home to die. The TRC, which conducted a detailed six-year review, found that physical, emotional and sexual abuse was rampant at the schools.[11] Further, the education provided at residential schools was substandard and many children barely attained basic literacy, furthering cycles of unemployment and poverty. Because these children grew up outside of their traditional family structures, bands and nations, they lacked a basic understanding of community relations, parenting and household management.

Although these events reside in the past, it is crucial to understand that the legacy of trauma is in fact generational and continues to be vividly experienced by Aboriginals today when they engage with the health care system. Past suffering results in systemic harm to subsequent generations through a loss of language and culture, inferior educational attainment, and the disruption of family structures.[13] Children of attendees demonstrate worse health status than children of non-attendees. Further, families in which multiple generations attended residential schools have greater distress, substance abuse and suicide than those in which only one generation attended.[14]

Unfortunately, most practicing physicians and nurses have no formal education about the disastrous impact of residential schools on Canadian Aboriginals. Medical schools do not include comprehensive teaching around traditional Aboriginal values or sensitive communication. This profound lack of understanding allows ongoing biases and racism to run unchecked. Rather than appreciating that present poor health conditions are influenced by social and historical events, many health care providers believe that Aboriginals are simply doomed to cycles of addiction, poor health, suicide and early mortality because of personal choice or racial inferiority.[15]

Institutional racism in Western health care organizations engendered by these negative biases continues to perpetrate trauma upon Aboriginal patients. Many patients articulate feelings of fear, shame and judgement when admitted to hospital, to the point that they prefer to leave before treatment is complete, further worsening health outcomes.[16] Racist comments reported in the Canadian media include physicians writing prescriptions with crossed out beer bottles, instead of legitimate medication or care plans.[17,18] I have personally witnessed an older Aboriginal woman admitted for severe medical issues being asked by a nurse, "So, did you fall down drunk?" Further, the institutional nature of hospitals, where physicians and nurses typically hold great emotional and physical power over ill and infirm patients, can mirror past events experienced at residential schools. As a result, survivors of residential schools may experience triggering of post-traumatic memories following hospital admission.[19]

Taking a historical view when interpreting present day health injustices is critical to progress cultural safety. Unless health care providers understand the root causes of current health outcomes, their biases and racist beliefs will contribute to the cycle of trauma and injustice. The following

bioethical analysis will clarify areas in which violations have occurred, while also striking a balance when advocating for solutions. Health care providers and institutions must serve the unmet needs of vulnerable Aboriginal patients, while also respecting their autonomy, diversity and resilience.

III. BIOETHICS ANALYSIS: Acknowledging Vulnerability while Promoting Self-determination

From a cultural safety perspective, all four foundational bioethics principles — personal autonomy, beneficence, justice, and non-maleficence — were violated in the process of colonization. Autonomy was quashed, whereby those in power took an extremely paternalistic view of the Aboriginal peoples, believing that "civilizing" them into Euro-Canadian culture was in their best interests. Unfortunately this approach led to little or no benefits and many harms when we consider past and current health inequities. We continue to see infringement of autonomy and lack of respect for persons in the form of institutional racism in health care institutions today.

From a justice perspective, the discussion can be framed as an issue of human rights, because it speaks to the degree of abuse perpetrated and the urgency with which a response is needed. Clearly, the process of colonization, illustrated by the residential schools, deprived Aboriginal Canadians of basic human rights on a societal level. The right to life, thought, religion, free movement, as well as basic needs including clean water, adequate nutrition, safety, education and housing were all systemically denied. Unfortunately, many of these gaps persist today. In 2015, a United Nations report declared that Canada's tolerance of violence towards its Aboriginal women and girls constituted a violation of human rights.[9] All Canadians, including health care providers and institutions, must recognize that human rights violations have occurred historically and continue to be perpetrated inside our own borders. Human rights are not just theoretical constructs from the past, or issues that concern persons and aid organizations in the third world. Work being done through the TRC aims to address these social injustices through policy, but this is beyond the scope of this paper.

On an individual level, Aboriginal patients are often described as vulnerable by health care providers. Vulnerability in health care can arise because of internal factors that affect ability to advocate for oneself, including physical illness, mental illness or substance abuse.[20] External factors include epistemic power hierarchies, where physicians and nurses hold the power to provide or deny treatment to patients. Acknowledging vulnerability is important because it calls attention to the need for special care and tailored resources to help Aboriginal patients navigate the care environment with safety and quality.

A. Alternate voices and perspectives

The bioethics concept of vulnerability is a nuanced one and must be handled with care. When we label a group as vulnerable, we risk being overly paternalistic and may excuse unjustifiable increases in social control.[21] Also, dwelling on vulnerability can perversely entrench the ideas it seeks to reverse, namely exclusion and stigmatization. Lastly, Aboriginal Canadians are an extremely diverse group, and labeling or generalizing does disservice to individuals who have met adversity with resilience, or do not feel defined by the dominant cultural historical narrative. In any agenda meant to reduce vulnerability, input from the central stakeholder — in this case, Aboriginal Canadians — is necessary to

ensure that solutions focus on unmet needs rather than further cementing misconceptions of internal deficiencies.

Canadian society as a whole is moving towards a better understanding of the challenges faced by Aboriginals. However, racism and lack of education persists and is evidenced by attitudes that seek to deny Aboriginals any special consideration or tailored aid strategies. Some believe, as in discussions around the validity of international aid, that aid only prolongs dependency.[22] This perspective belies the fact that Aboriginals continue to face institutional racism and unfair social conditions. Under these circumstances, largely created and propagated by the majority in power, we have an absolute ethical obligation to redress wrongs through research, education and policy change.

IV. CURRENT AND FUTURE DIRECTIONS: HEALTH CARE PROVIDERS AND INSTITUTIONS EMBRACING CULTURAL SAFETY

In many parts of the world with a colonial history, including Australia, New Zealand and Canada, health care institutions are beginning to take steps to improve cultural safety.[23] This starts with the creation of an education program, such as the San'yas Indigenous Cultural Safety training program in British Columbia, Canada.[24] These programs focus exclusively on the care of Aboriginal patients, rather than cultural minorities in general, and aim to equip practitioners with the knowledge and communication skills needed to provide a safer health care experiences for their Aboriginal patients. Cultural safety training can be unexpectedly painful for health practitioners because it prompts self-reflection into one's own biases and challenges conscious or subconscious racism. Further, it forces the acknowledgement of one's own elevated status and privilege, and how this power differential impacts the care of Aboriginal people.[3]

Health care institutions have also developed specialized roles, including Aboriginal Patient Navigators (APN), to bridge the cultural trust gap between health providers and Aboriginal patients.[25] The involvement of these trained individuals, who are often Aboriginal themselves, has been shown to decrease stress and anxiety for Aboriginal patients in hospital, as well as improve their access to social supports. Many health care institutions have also created "safe spaces" for patients of all faiths to practice and hold gatherings. These spaces have enabled Aboriginal patients to hold traditional ceremonies, including smudging, allowing them to integrate aspects of traditional medicine while still receiving Western treatments.[26]

What is lacking in much of the discussion about cultural safety locally and internationally is meaningful data collection and research around how effective the above interventions are.[27,28] Key to the concept of cultural safety is that quality and safety are judged by Aboriginal patients, not by health care providers or institutions. The involvement of Aboriginal people in the creation and evaluation of any program is essential to ensure that programs truly fill unmet needs. Lastly, institutions have the potential to improve care for individual patients, but without a larger societal commitment to advance social justice for Canadian Aboriginals, beneficial change will be hampered.

CONCLUSION: RESOLUTION WITHIN TEAM?

We do not know the details of the interactions that led to a fracturing of trust between Makayla's family and the medical team. However, specific recommendations could be made for future such conflicts aiming to improve mutual understanding and respect. Upon admission, the team could offer the services of an Aboriginal Patient Navigator. If no APN role exists, the institution should urgently

consider creating one. The team could benefit from specific training in cultural safety, and perhaps this should become a mandatory expectation for any front line health provider. A safe space could also be offered to Makayla to facilitate integration of traditional medicine practices within the Western institution. Consideration could also be given to moving Makayla to her home community, allowing her to continue her treatment in relative comfort. Lastly, any such programs need to be evaluated by Aboriginal patients and their families to ensure unmet needs are being served.

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