

HEALTH ETHICS | SOCIETY | SCIENCE | TECHNOLOGY

BRAINSTORM

MAGAZINE REMUE-MÉNINGES

ISSUE #1 / SUMMER 2019

Key issues in Canadian health ethics

Including contributions by

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Michael Orsini

Michèle Stanton-Jean

Fae Johnstone

Caroline Tait

Tracey Rickards

Jennifer Johannesen

Ma'n Zawati

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Tracey Galloway

Sarah Bowen

INTRODUCTION

Dear readers,

For several years now, our team has nurtured the idea of developing a magazine capable of bridging the gap we currently see between bioethics scholars, health practitioners, and the Canadian public. In the current landscape, public discussions about health ethics in Canada do not always get at the specific challenges we face as Canadians, especially given our regional, linguistic, and cultural diversity. We also find that, too often, discussions about these challenges occur without the involvement of important stakeholders (i.e., the people implicated in or affected by the discussed issues). Issues such as the right to die, the healthcare needs of minorities, and the implications of clinical research all call for significant public dialogue. Further, mainstream discussion about healthcare and health ethics sometimes fails to examine complex histories of systemic violence, cultural differences, relations of power, service provision for different linguistic groups, and the everyday lived experiences, needs, and values of marginalized groups. The goal of *Brainstorm/Remue-méninges* is to bring academic discussion out into the open; to facilitate inclusive dialogue and present scholarly topics in more accessible ways.

We hope that the format of a magazine allows for questions and gaps in knowledge related to all of these topics to be addressed in an effective and accessible manner. In the spirit of the linguistic duality of our country, *Brainstorm/Remue-méninges* will publish contributions in both English and French.

For this inaugural issue, we have invited a range of contributors to write about what they take to be the most important and pressing health ethics challenges in Canada. We sought a multitude of perspectives and engaged with scholars, advocates, and policymakers alike, to bring our readers insights from different disciplines.

Several of the contributions in this issue highlight the human cost of marginalization within our healthcare system: Caroline Tait's exploration of the foster care

system for Indigenous children, the Qaujigiartiit Health Research Centre's research on culturally-sensitive end of life care in Nunavut, Fae Johnstone's and Tracey Rickards' critical call for inclusive health and social services for LGBTQ2s+ communities, Jennifer Kilty's discussion about medical aid in dying for prisoners, and Sarah Bowen's treatment of language barriers in Canada.

Michael Orsini's contribution – a rejoinder inviting disability perspectives to the table – and Michèle Stanton-Jean's plea for the recognition of the wealth of knowledge and expertise held by the elderly population both show how diminished in value our discussions become when key voices are missing. Jennifer Johannesen shows us that even when important stakeholders are involved, the ethical implications of their involvements can be overlooked due to idealized notions of collaboration fed by unreflective enthusiasm. Ma'n Zawati's contribution presents us with a case in which nearly all of us are stakeholders: the development of smartphone-integrated health technologies.

There are without a doubt many important health ethics challenges left unaddressed in our first issue (e.g., equality and education as determinants of health, the undermining of healthcare by corporate interests, the issue of poor access to primary healthcare). Our hope is that the diversity of contributions and topics covered stimulates you and inspires you as readers to delve into some of the yet uncharted areas of bioethics. We also hope to raise awareness about topics that matter to all stakeholders and generate new directions in which to take our health ethics discussions. We welcome feedback on every aspect of our first issue and hope to see *Brainstorm/Remue-méninges* progress in ways that reflect the concerns and experiences of our readers!

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BRAINSTORM

ABOUT THE MAGAZINE:

Brainstorm Magazine/Remue-méninges fosters an inclusive space for dialogue about key ethical issues shaping the current social, medical, and scientific context of healthcare. *Brainstorm Magazine/Remue-méninges* is committed to developing a space to sustain innovative and collaborative responses to the problems surfacing in this context. Through a strong commitment to diversity, this platform intends to bridge barriers across languages, cultures, and nations.



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THINKING ETHICALLY WITH DISABILITY



MICHAEL ORSINI is Professor in the School of Political Studies at the University of Ottawa, where he specializes in health policy and politics and critical approaches to public policy.

ETHICS DEBATES ARE MISSING A DISABILITY PERSPECTIVE

In Canada, the Supreme Court's high-profile decision in the Carter case, which opened the door to assisted dying, cried out for a disability analysis. However, with the exception of passionate advocates such as Catherine Frazee, public debate excluded the perspectives of disability advocates. As the Council of Canadians with Disabilities and the Canadian Association for Community Living made clear in its Factum to the Supreme Court of Canada in the Carter case, we should counter the idea that assisted dying applies only to terminal illness, not disability.

Many disabled people, they explain, “are not immune from internalizing the idea that they are leading lives that have less value than those of persons who do not have disabilities. This can result in such persons expressing the belief that they ‘would rather be dead than alive with a disability.’ The notion that ‘it is better to be dead than disabled’ can be very powerful, particularly for someone who has not yet experienced disability or who is surrounded by persons who reinforce this negative stereotype” (1).

These types of negative stereotypes about disability have important consequences. Disability rights perspectives are often framed as extreme, partial, and overly emotional, while the perspectives advanced by bioethicists and other experts are seen as balanced, reasoned, and nuanced. In

Some of the most contentious issues related to health care and bioethics pertain to disability, but disability perspectives are often missing from public and expert discussion. The exclusion of these voices is a central and pressing challenge for Canadian health ethics.

fact, ethics debates in the field of healthcare often occur in the absence of the perspective of persons with disabilities.

How can we explain this?

ABLEISM IS MORE THAN AN “ISM”

One answer might be found in ableism, which disability activist Lydia X. Z. Brown defines as “the systematic, institutional devaluing of bodies and minds deemed deviant, abnormal, defective, subhuman, less than” (2). For disabled people moving through the world, however, ableism is more than an “ism”: it is a structuring feature of everyday life.

Ableism can be felt in dramatic ways, or it can be seemingly mundane and become a taken-for-granted feature of our culture and politics. Recently, Bronwyn Berg, a woman from Nanaimo, BC, found herself screaming “no, no, no” to a stranger who grabbed her wheelchair and pushed her down the street without her consent. “The point is never, ever touch a wheelchair without asking,” Berg told the CBC. “Our assistive devices are a part of our body. We aren’t furniture that can be moved around” (3).

The type of behaviour experienced by Berg, which disabled people say is frustratingly common, is only possible in an environment in which disabled people are not seen as fully human. As Berg explains, disabled people’s bodies and minds are viewed as not belonging to them, so why bother having to ask before grabbing someone’s wheelchair?

MOVING BEYOND NARRATIVES OF “OVERCOMING” DISABILITY

Even if able-bodied folks grudgingly acknowledge the humanity of disabled people, they often find comfort in the familiar trope of “overcoming” disability. The media revel in narratives of individuals who succeed or flourish “despite” their disability. In *Brilliant Imperfection*, disability author and activist Eli Clare describes how the “language of overcoming” is a potent reminder of the refusal to centre disability experiences: “Sometimes disabled people overcome specific moments of ableism — we exceed low expectations, problem-solve lack of access, avoid

nursing homes or long-term psych facilities, narrowly escape police brutality and prison. However, I’m not sure that overcoming disability is an actual possibility for most of us. Yet in a world that places extraordinary value in cure, the belief that we can defeat or transcend body-mind conditions through individual hard work is convenient. Overcoming is cure’s backup plan” (4).

Experts in the field of bioethics, among others, need to take seriously their own gaps in thinking and work to appreciate the complexity of the lived experiences of disability. How could someone reasonably desire being disabled, they might ask? Surely, we all aspire to live a life free of disability? Well, we might think differently if we actually paid attention to the multiple perspectives coming from disability communities.

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ABLEISM CAN BE FELT IN DRAMATIC WAYS, OR IT CAN BE SEEMINGLY MUNDANE AND BECOME A TAKEN-FOR-GRANTED FEATURE OF OUR CULTURE AND POLITICS.

HOW DID YOU COME TO WORK ON THIS ISSUE?

I began to study disability politics and policy while doing research on the politics of contested illnesses and the role of civil actors in framing contested conditions. One of the case studies I chose was autism, even if I was unfamiliar with its sheer complexity and the key role that individual autistic people were playing in how autism is understood.

MEDICAL ASSISTANCE IN DYING (MAID) AND DISABILITY

In 2018, the Canadian Association for Community Living (CACL) and the Council of Canadians with Disabilities (CCD) raised concerns about the regulations in place for MAiD (1). These organizations suggest that we need to monitor this procedure more closely to safeguard individuals with disabilities who could be vulnerable in the current system. Instead of resorting to assisted death, the suffering of individuals with disabilities could be addressed by a better health care system and greater access to support and care for themselves and their caregivers. As Roger Foley, president of CACL suggests, disabled individuals need to be offered “assistance in living” before they are offered medical assistance in dying.

WHAT IS ABLEISM?

As Michael Orsini explains in his text, ableism is not just a concept. Ableism designates a set of social beliefs and biases (both conscious and unconscious) that devalue the lives of individuals living with disabilities. An off-handed joke about a colleague with a learning disability, a concert venue inaccessible by wheelchair, or general assumptions about what disabled individuals want and need by able-bodied persons are all ableist in different ways. Ableism has material consequences on disabled people’s lives and can lead to discrimination, prejudice, stigma, and violence.

A LANDMARK DISABILITY CASE SOUTH OF THE BORDER: THE ASHLEY TREATMENT

In the United States, the Ashley X case quickly gained a flurry of national media attention and polarized public opinion on disability. Ashley X is a Seattle woman with static encephalopathy, a type of permanent or unchanging brain damage causing severe developmental disabilities. Ashley’s parents dubbed her the “pillow angel” because she apparently does not move from the position in which she is placed, usually with her head in a pillow. Claiming that she had the mental capacity of an infant and justifying their actions as an act of love, Ashley’s parents “treated” her with growth attenuation via high dose estrogen, a hysterectomy, breast bed removal, and an appendectomy. They argued that this would protect their daughter from sexual violence while in institutional care or when they would no longer be able to protect her or advocate on her behalf. The case brought loud denunciations from disability rights activists, who accused the parents of robbing Ashley of her sexual autonomy and dignity. *(Text by Michael Orsini.)*

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DYING ON THE INSIDE: MAID FOR PRISONERS

JENNIFER M. KILTY is Associate Professor in and Associate Director of the Department of Criminology at the University of Ottawa. Her research examines the health experiences of incarcerated people, carceral segregation practices, and the criminalization of HIV nondisclosure.



For decades, medical assistance in dying (MAiD) has been a lightning rod for intense ethical debate in many countries, including Canada. In 2015, the Supreme Court of Canada brought forth a unanimous decision that struck down the federal prohibition on physician-assisted dying. Later, in 2016, Parliament passed Bill C-14,

decriminalizing MAiD in certain cases and laying out the parameters regarding how to and who can access it – the most contentious criterion being that the individual must have a “grievous and irremediable” health condition (1). This means that the applicant must suffer from an incurable illness or disability that is in an “advanced state of irreversible decline in capability,” endure intolerable physical and psychological suffering, and have their natural death be “reasonably foreseeable” (1). Ambiguity remains regarding how to interpret this last point because the individual does not need a prognosis for how long they have left to live nor a diagnosis of a terminal condition to be eligible. So, what does it mean to have a “reasonably foreseeable” death? Since the law does not prohibit someone suffering from mental illness from accessing MAiD, how are we to determine that their death is reasonably foreseeable or that their suffering is intolerable?

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REQUESTS FOR MAID ARE EVEN MORE COMPLICATED IN CARCERAL CONTEXTS

MAiD becomes even more complicated in carceral contexts where incarcerated men and women have higher-than-average rates of mental illness – for example, upwards of 80 per cent of federally sentenced women meet the criteria for a diagnosis of mental disorder (2) – and where autonomy, free will, and choice are under constant threat by the very nature of incarceration. The current guidelines for federal prisoners to access MAiD require that the first assessment be conducted internally by an institutional physician or nurse practitioner and the second assessment by an external evaluator. This process could pose a potential conflict of interest should the internal assessor prevent the request from being sent out for second review as it leaves all the decision-making power up to employees of Corrections. This blurs the boundaries between the powers that punish and those that are responsible for health and well-being. In order to maintain this important divide and to sustain the much-needed connections between community-based health and mental health service providers and incarcerated people, all aspects of health care should take place in the community, which would also help to strengthen the likelihood of successful reintegration post-incarceration.

The Correctional Investigator has rightly recommended a ban on medically-assisted death in prison, contending that it breaches the correctional system's legal and ethical obligations to preserve life (3). This would require that all assisted deaths for prisoners be performed in the community by medical practitioners who do not work for Corrections – an important separation of the power over life and the power to punish. He also proposed that greater access to “parole by exception,” which allows prisoners to be released into the community on compassionate grounds, be made available. This last point is significant, given that most requests for compassionate release are rejected, which may unintentionally increase MAiD applications. This fact is especially problematic for prisoners with terminal conditions and elderly prisoners, including those who do not have a terminal illness but rather a host of non-lethal conditions that constitute a level of frailty that the courts have accepted as meeting the “reasonably foreseeable natural death” requirement.

OUR RESPONSIBILITY TO PROTECTING THE HEALTH AND WELL-BEING OF INCARCERATED PEOPLE

While I agree with these recommendations, they do not go far enough to protect the health and well-being of imprisoned people. Incarceration is a desolate experience that is well-recognized as causing mental distress and aggravating symptoms of existing mental health conditions – especially for those who are isolated in segregation and deprived of normal human interaction (2). For prisoners who are particularly negatively-affected by incarceration, we must question whether austere conditions of confinement place already vulnerable patients at risk of premature death. How do we assess whether the harm of imprisonment is at the root of the psychological suffering that leads to a MAiD request? If we cannot, approving a request made on psychological grounds is akin to the death penalty.

It is worth remembering that the MAiD eligibility criteria mandate that the applicant be in an “advanced state of irreversible decline in capability” and experiencing intolerable suffering that cannot be relieved under conditions the person considers acceptable. Unless the state is willing to leave a citizen in conditions in which they would rather die, we must consider alternatives to confinement – especially for the terminally ill, the elderly, and those suffering from mental illness – as well as how to improve existing conditions of confinement so as to relieve suffering to the degree that the individual's decline in capability could be reversed. In this way, MAiD requests may inadvertently help to demonstrate just how harmful imprisonment is, opening the door to furnishing public and political support for less restrictive and more humane approaches to punishment.

Ethically, it would be wise not only to separate MAiD requests from Corrections, but to do so for all aspects of health and mental health care, which would help to alleviate the pain of imprisonment and to maintain the community connections that are essential for successful reintegration.

HOW DID YOU COME TO WORK ON THIS ISSUE?

I attended a panel presentation on medical aid in dying in fall 2016 at the Faculty of Law at the University of Ottawa. The focus was on the implications of the decision of the Supreme Court of Canada and what we could learn from other countries that have already legalized the practice. Given my research focus on the health of incarcerated people and the harms of incarceration, I immediately began to think about how this decision could problematically facilitate the deaths of incarcerated people, as well as how it could showcase the exceptional pains of imprisonment in a new and poignant way.

WHAT IS MEDICAL ASSISTANCE IN DYING (MAID)?

Medical assistance in dying, or MAiD, is a process whereby Canadian citizens aged 18 or older can apply to receive professional medical assistance by way of prescribing or administering a substance that causes the death of the person who has requested it. (Text by Jennifer Kilty.)

WHO IS ELIGIBLE FOR MAID ACCORDING TO CANADIAN LAW?

According to the organization Dying with Dignity Canada, to be eligible for MAiD, one needs to have an illness, disease, or disability that is considered to be "grievous and irremediable." The criterion that has sparked the most debate and confusion, however, is the one specifying that a person's natural death must be "reasonably foreseeable." Many MAiD advocates argue that this criterion excludes patients who are not terminally ill but who are suffering physically and emotionally and wish to access MAiD (1).

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SOME KEY DATES FOR MAID IN CANADA

2016

June

Members of the Canadian Parliament formalize legalized assisted dying for eligible Canadian adults by passing Bill C-14 (2).

2015

January

The B.C. Civil Liberties Association appeals the Supreme Court of Canada's decision to ban doctor-assisted dying.

February

In a unanimous decision, the Supreme Court of Canada strikes down the federal prohibition on physician-assisted dying. The Court rules that doctors should be able to provide assisted suicide in some specific situations.

2014

June

The National Assembly in Quebec passes Bill 52, a landmark end-of-life care bill, also known as the "dying with dignity" law.



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IN CANADA, A SERIOUS CHALLENGE FOR HEALTHCARE PROVIDERS AND FOR HEALTHCARE ETHICS OCCURS WHEN AN OBVIOUS HEALTH RISK EXISTS FOR A GROUP OF PEOPLE, BUT, DUE TO JURISDICTIONAL BARRIERS ACROSS FEDERAL AND PROVINCIAL/TERRITORIAL GOVERNMENTS AND MINISTRIES, THE IDENTIFIED RISK IS DEALT WITH OUTSIDE OF THE HEALTHCARE SECTOR.

CHILD WELFARE: A HEALTH AND ETHICAL CRISIS FOR INDIGENOUS CHILDREN AND THEIR FAMILIES

In Canada, a serious challenge for healthcare providers and for healthcare ethics occurs when an obvious health risk exists for a group of people, but, due to jurisdictional barriers across federal and provincial/territorial governments and ministries, the identified risk is dealt with outside of the healthcare sector. The implementation of child protection services in Canada is one such example, notably with respect to the apprehension and foster placement of First Nations, Métis, and Inuit children. It suffers from the absence of professional input from psychiatry, psychology, developmental pediatrics, Indigenous healers, and mental health advocacy groups regarding the known negative impacts that child welfare practices can have on the health and development of Indigenous children.

THE OFFICIAL PUBLIC STORY

For current child welfare systems to function, children taken into care need to be understood as possessing a high degree of emotional resilience and malleability. This means that the State thinks that once a child is placed in a home with a foster “mom” and “dad,” all threats to the child’s mental and physical well-being go away. The State assumes that the child will naturally adjust and thrive in their new home (1), which enables them to portray this kind of crisis intervention as necessary to protect children who are in danger.

But this is not how things actually work. Health care professionals and the health care system are rarely involved in decision making

about the needs of children taken by child services or currently in foster care. Unless a child exhibits clear signs of psychopathology, significant developmental delay, or severe emotional distress, they will likely never be assessed by a mental health professional during their foster placement. This lack of assessment is particularly alarming in cases involving First Nations, Métis, and Inuit children. While in care, Indigenous children are unlikely to see an Indigenous healer or therapist who speaks their language, knows their culture, and understands the intersecting risks of inter-generational trauma and child welfare involvement from an Indigenous perspective.

THE RISKS OF FOSTER CARE

In 2018, my colleagues and I wrote an article that raised a red flag about mental health and developmental risks for First Nations and Métis children involved in the child welfare system. These risks are still unacceptably high, despite decades of child welfare reports documenting the effects of child welfare practices on healthy childhood development (1). Our work reveals that health ministries – including politicians, professional health bodies (e.g., Canadian Psychiatric Society, Canadian Medical Association, Canadian Academy of Child and Adolescent Psychiatry), and systems of care across the country – respond inadequately to what is a documented and unaddressed mental health crisis occurring among the most vulnerable children in our country. However,

despite the level of risk, professional medical bodies and practitioners remain focused on pre-foster placement risk and virtually ignore the compounding impact of child welfare involvement (2). If we care about the well-being of Indigenous children put into foster care, we should involve professionals in the evaluation of these risks.

There are many risks involved for children taken from their families and entering the foster system. First, it becomes difficult for children to form strong and lasting bonds within their biological families. Moving homes while in care also means moving schools and moving away from people they are close to (e.g., teachers, support workers, classmates, friends, other foster children). Children taken into foster care or adopted by a non-family member also risk losing all connections to their biological families and to their Indigenous language, culture, and community. Their risk of experiencing physical, sexual, and emotional abuse at the hands of a foster parent, a foster child, or other adults who have access to them also increases with extended and multiple foster placements. In some instances, Indigenous youth “age out” of the system at 18 years of age, without any connection to their biological or foster families. Indigenous youth involved in the foster care system are also overrepresented in youth correctional facilities, gangs, and street life, and many eventually experience the same challenges that their parents did in raising their children, perpetuating inter-generational child welfare involvement.

THE STATE FAILS AS “PARENT”

Child welfare reform is front and center in the minds of Indigenous peoples across Canada, who want to see sweeping legislative changes, including the creation of First Nations-, Métis-, and Inuit-specific child welfare legislation that leads to self-determined approaches to protecting and caring for Indigenous children and families. Central to this effort is a focus on prevention and a recognition that basic human rights, not to mention child and Indigenous rights (3, 4), must be central in child welfare legislation, policy, and daily practice. Unless this happens, vulnerable Indigenous children and families will continue to experience inter-generational impacts directly resulting from child welfare involvement.

The irony (or absurdity), one could argue, is that in the present-day context of child welfare practices across Canada, the State as the “parent” of vulnerable Indigenous children fails them on multiple fronts. As Mi’kmaq Elder and child advocate Joan Glode sums up: “The language is lovely. The language in child welfare is that the duty of care of a child welfare authority is to act in the capacity of a wise and compassionate parent. A wise and compassionate parent doesn’t do all the things that happen to these kids” (5).

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THE SITUATION OF INDIGENOUS CHILDREN IN CANADA

First Nations, Métis, and Inuit children who are taken into foster care commonly live in poverty. Most often, they are being raised by a single mother receiving social assistance who has limited social support to rely on. The everyday life of these families is almost always burdened by overcrowded housing, food insecurity, and frequent household moves (1). Intergenerational trauma resulting from the brutality of European colonization (e.g., residential schools, forced relocation, and appropriation of traditional lands) can lead to cases of adult mental illness, substance abuse, and domestic violence. These precipitating factors draw State surveillance to the family: in fact, the majority of Indigenous children come into foster care because of parental “neglect” (those factors beyond the parents’ control) and not because of “abuse” (2). Even before they are put into foster care, these children are often vulnerable and are at elevated risk of experiencing short- and long-term mental health and developmental problems. (Text by Caroline Tait.)

SOME NUMBERS ABOUT INDIGENOUS CHILDREN IN FOSTER CARE

First Nations, Métis, and Inuit children across Canada are the children most likely to be placed in foster care (3). They typically remain in foster care longer, are at risk of multiple apprehensions throughout their childhood, and are at greater risk of being moved to multiple foster homes (e.g. typically 10 to 30 times throughout their childhood) (1). (text by Caroline Tait)

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PROVIDING CULTURALLY SENSITIVE CANCER AND END-OF-LIFE CARE TO THE INUIT POPULATION OF NUNAVUT

SIDNEY HORLICK is a research assistant at the Qaujigiartiit Health Research Centre in Iqaluit, where she works on a variety of research projects and program evaluations. She started to work on this issue when she joined Qaujigiartiit in mid-2017.

MARIA CHERBA is a research assistant at the Qaujigiartiit Health Research Centre in Iqaluit and a PhD student at the University of Montreal, where she is doing a project on patient-medical team communication in surgical oncology. She started to work on the Nunavut Cancer and End-of-Life project and to learn about culturally appropriate care for Inuit when she lived in Iqaluit in 2017.

MADELEINE COLE is a family doctor in Iqaluit who has a longstanding interest in providing and thinking about culturally safe care through partnership, continuity, and integrity. She has presented at academic fora on Indigenizing medical education and Becoming a Better Ally to Indigenous Canada, as well as on health ethics in the hospital setting.

GWEN HEALEY AKEAROK is the executive and scientific director of the Qaujigiartiit Health Research Centre in Iqaluit, where she is conducting community-based research to improve the health of Nunavummiut. This issue came about in a discussion among the members of the ethics committee at Qikiqtani General Hospital about finding ways to build culturally-appropriate and supportive processes and tools into the healthcare system.

TRACEY GALLOWAY is an Assistant Professor at the University of Toronto Mississauga, where she conducts research on Indigenous health, food security, and public health policy. She decided to study the cancer experience from the patient and family perspective after learning of the challenges faced by Nunavut families who fly south for treatment of serious illness.

One of the greatest healthcare ethics challenges in Canada is responding to Indigenous healthcare needs in culturally appropriate and responsive ways. Practices that are sensitive to patient health needs and beliefs, cultural values and practices, and linguistic requirements are vital to the provision of patient-centered care and are most likely to produce positive outcomes. The Truth and Reconciliation Commission calls for an increase in the number of Indigenous doctors and nurses and delivery of cultural competency training for all healthcare providers (1). However, while the government of Nunavut has started developing initiatives to achieve these goals, there is a great and continued need for improvement (2).

THE NUNAVUT END-OF-LIFE PROJECT: A WINDOW INTO THE EXPERIENCES OF HEALTHCARE PROVIDERS, PATIENTS, AND THEIR FAMILIES

Several systemic factors stand in the way of culturally appropriate care in Nunavut. For example, the vast majority of health providers come from outside the territory and receive limited to no cultural orientation upon arrival, which significantly impacts their ability to understand the population they serve and provide care that integrates Inuit cultural norms and practices. In addition, there are limitations to the breadth and scope of health services that can be provided to patients within Nunavut. Patients requiring more advanced care must travel outside the territory to southern tertiary centres. These two conditions combined have created an environment that requires an innovative approach to culturally appropriate cancer and end-of-life care, which we currently lack.

In a discussion among the Qikiqtani General Hospital Ethics Committee, care providers described a disconnect between the territory's current handling of end-of-life and cancer and what they considered to be culturally sensitive and appropriate for Inuit. In response, we initiated the Nunavut End-of-Life Project to examine patient, provider, and family experiences, to help us develop and implement culturally appropriate cancer and end-of-life care strategies and resources. Through these discussions, we found that, while

certain aspects of cancer and end-of-life care in Nunavut align with cultural values, others require improvements.

SPACE FOR IMPROVEMENT IN CULTURALLY SENSITIVE CARE

Patients, families, and health professionals described aspects of care that they felt were positive supports and integrated Inuit cultural values, such as inclusion of the family in care and decision-making processes, access to country food (traditional Inuit food), and patient support groups facilitated by or involving Elders. Unfortunately, this kind of care isn't always available. For example, although patient support groups involving Elders are provided in some communities, they are not always accessible across the territory, so not all families have such supports.

There are also several key aspects of care that can be improved, not just made more accessible. For example, our participants expressed a need for culturally appropriate mental health supports, such as services delivered in Inuktitut. The importance of Inuit family values and relationships were emphasized – how keeping the family together as much as possible during cancer and end-of-life care would be a culturally appropriate approach to supporting families during that difficult time. They also expressed the importance of offering better Inuktitut language services throughout care, from diagnosis onward: one participant said “if there's

a language barrier, then that's when you bring an interpreter in... If they had done that with my grandmother, I think they would have been able to catch the cancer sooner than they had done.”

The importance of relationships was also emphasized in the patient-provider-family context. Patients and families value relationships with their health care providers and want them to have a connection with their community, which is consistent with Inuit values and relational ways of knowing (3). One participant noted that her grandmother's care was positively impacted by having a connection with carers: “the homecare workers, they are some of the hardest workers in town. And I think that's because they're primarily from [here] – they know the language, they know the family history.” The importance of full-time nurse employment and reduction of the number of practitioners on fly-in fly-out contracts was also emphasized, and some health professionals coming from outside the territory reported the need for more education about Inuit culture.

As a research team, we will be using the findings from the Nunavut End-of-Life study to create a decision-making tool for health professionals, in the hopes of providing a way forward that truly reflects and respects Inuit values. These services are essential to support the needs of Inuit cancer patients and patients at the end of their lives.

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LGBTQ2S+ ACCESS TO ETHICAL HEALTHCARE IN ATLANTIC CANADA: AN INTERVIEW WITH TRACEY RICKARDS (RN, PHD)

Interview by **CORINNE LAJOIE**, for *BRAINSTORM/REMUE-MÉNINGES*.

CL: Dr. Rickards, you've been a nurse for 33 years and have what we might call a true 'insider' perspective on the Canadian healthcare system. I wanted to ask you, what do you think it means to deliver patients ethical healthcare?

TR: I think that to truly deliver ethical healthcare, one must have some awareness of people who identify as LGBTQ2S+, what it means to live on the margins, and an understanding of the power to control lives in the margins. If it were as easy as telling people to treat others with kindness and respect, we wouldn't be having this conversation. But it's not that easy, because behavior is often censored and policed by people who control the dominant discourse. While people working in the institutions have changed how they approach gender and sexual minority identities, the impediment remains systemic.

CL: What do you think is the central challenge faced by LGBTQ2S+ folks accessing healthcare?

TR: In my opinion, the greatest challenges for the entire rainbow community is the attitude with which healthcare of any kind is provided. Historically, we know

that many lesbians and gay men have avoided cancer screening because of fear of rejection and humiliation upon having to disclose their sexual orientation. Many individuals on the LGBTQ2S+ spectrum avoided regular basic healthcare due to heteronormative norms. We used to think that sexual orientation had nothing to do with healthcare needs. Now, we understand that denying people's identities does not acknowledge the very essence of their lived experiences – of being different from the norm.

CL: Absolutely, so it's essential to understand how people identify, particularly when they are different from the norms our healthcare and society at large tend to assume. Do you have an example of an interaction that can be illustrative of this broader, systemic problem about access to inclusive care?

TR: My wife has had a number of health issues over the years. We noted a change from when we first engaged with the healthcare system to now, in terms of how our same-sex relationship was received. We don't see it as an issue anymore, but it certainly was an issue at the start. For example, prior to 2005 and the legalization of same-sex marriage, when registering for care at our local hospital, the Administrative Assistant,

who knew me because I was staff at the hospital, asked my wife to specify her next of kin. "Tracey Rickards, she's my domestic partner," she replied. We were told that wasn't an accepted designation.

Since 2005, and given our status as legally married, some attitudes have improved – although the electronic records program used by the hospital still won't allow us to identify me as my partner's 'wife,' and requires us to identify as 'spouses' instead! Okay, I can deal with that! The hospital employee we spoke with had to explain that the program would not let them use our preferred designations, that is, that a woman could not have a wife, nor a man have a husband. The frustration on the part of the hospital administrative staff was one of the drivers that finally moved the system forward. Other drivers included LGBTQ2S+ community members asking the Human Rights Commission to weigh in. Eventually, these raised voices exerted enough pressure to result in concrete changes.

CL: And in your experience as a registered nurse, have you had to face similar issues or fight similar biases in the healthcare system? Do you have an example of the kinds of problems nurses have to deal with?

TR: I'm not sure that all nurses whose gender and sexuality have never been challenged have consciously considered the ramifications of what it means to be part of a sexual minority. I can't say that all nurses think that sexual orientation or gender identity are an important part of a person's identity as a whole. Many are stumped when confronted with anything that falls outside the heterosexual norm. In my experience as a nurse, I have witnessed the 'uncomfortable pause' when a patient discloses their sexual orientation or gender identity to a nurse. The nurse stutters and stammers while processing the information, eventually landing on the 'right' way to respond. Meanwhile, the patient is very much aware that this nurse, who will be providing them with care, had to stop, process, and decide on a course of action; it wasn't second nature for them to simply acknowledge the information and move on from there. The good news is that the newest generation of nurses have lived in a world in which sexual orientation has not been illegal and therefore it is less marked as different or 'other'. In my mind, and as an educator of the next generation of nurses, there's

hope for the future if we don't back off from raising awareness about the importance of gender identity and sexual orientation.

CL: I'd like to ask you a bit more about how these issues affect LGBTQ2S+ folks living in rural settings, for example in the Atlantic provinces, which is where you live and teach. Do you think that there are specific issues around care for LGBTQ2S+ in these types of settings?

TR: Yes, definitely. Most of Atlantic Canada is considered rural, and, working and practicing here, I've encountered a large dose of conservative and very religious perspectives. Rural areas are challenging places to obtain and retain healthcare professionals, let alone professionals with adequate training to serve the social and medical needs of LGBTQ2S+ patients. The charm and challenges of rural life are that everyone may know everyone's business. A gay, lesbian, gender-non-conforming, or transgender person, for example, is less likely to come-out in a system where privacy is a concern. Access to appropriate and non-judgmental care is one of the biggest barriers for the LGBTQ2S+ community, particularly in rural settings. Healthcare providers are all 'taught' to provide the best care possible and to advocate for the needs of clients/patients, but we know that it's not always the case, partly because of conservative or refractory convictions. Schools of nursing and medicine are recognizing the urgency to educate healthcare providers to understand that self-expression and identity matters, in a way they might never fully comprehend. Younger, more open-minded healthcare providers will eventually replace those with more traditional views, but this is still no guarantee of ethical healthcare.

Overall, I think that non-judgmental, open-minded care is what is required to improve how LGBTQ2S+ communities experience care. But this will not happen until people acknowledge that there ARE margins and that there are people whose lives are censored and discussed as being outside the 'norm', whatever that is! It is that simple, and just that difficult.

CL: Thanks a lot for speaking with us!

F AE JOHNSTONE

(they/she) is an educator, organizer, and writer focused on gender, sex, sexuality, and health based in Ottawa, Ontario, on unceded and unsundered Algonquin territory.



TRANS HEALTH AND WELLNESS: THE CRISIS NO ONE IS TALKING ABOUT

According to a recent study by the Trans PULSE project, a community-based research project investigating the experiences of trans people, more than half of trans people in Ontario have depressive symptoms consistent with clinical depression. 43% have a history of attempting suicide and 35% have considered suicide within the past year (1). Despite this crisis – a crisis we have the evidence to prove and for which clear solutions exist – our government and health and social services have failed to respond. The failure to recognize the issues faced by trans people and to develop responses to these problems is a central issue for Canadian health ethics today.

THE LIVES OF TRANS PEOPLE ARE SHAPED BY SYSTEMIC VIOLENCE: THE NUMBERS IN CANADA

Trans people and Canadian institutions have a bad history. For decades, Canadian institutions were complicit in pathologizing trans identities, treating trans people as “crazy”, mentally ill, and fundamentally deranged. Despite recent shifts towards a more inclusive approach – such as the introduction of the Gender-Affirming Care model, where trans people are trusted as the experts in their own lived experiences and needs – this “history” is our recent past and elements of it remain embedded across our health and social services to this day.

As we aim to do better by, for, and with trans people, it is crucial for us to acknowledge that the negative health outcomes of trans people have nothing to do with their transness and everything to do with the social, political, and economic violence enacted against their communities.

Trans PULSE also reports that 20% of trans people have been physically or sexually assaulted and an additional 34% have been verbally threatened or harassed, but not assaulted. 83% of trans people in Ontario have avoided public spaces because they feared being harassed, perceived as trans, or outed. Three in 5 people will intentionally misgender a trans person. One-third of younger trans youth (ages 14-18) and half of older trans youth (ages 19-25) report missing needed physical health care during the past year, and even more missed needed mental health care. Twenty-one percent of trans people have avoided emergency departments when they needed it specifically due to fear of discrimination. Additionally, 50% of trans people in Ontario with family physicians report those physicians being uncomfortable discussing trans health issues. Approximately 38% reported at least one negative experience with their physician related to

their trans identity (1).

The lives of trans people are thus fundamentally shaped by the systemic violence they experience every day. Trans people are not ill or deranged. They have no need, want, or use for pity. They are resilient and brilliant, and they have survived decades of violence. If we are to do better for trans communities, we must acknowledge the realities of the harms done to trans people in this country and the ways in which our health and social services continue to fail trans people. Trans people are a marginalized population that experiences heightened risks. Their rights are explicitly protected in every provincial human rights code and the Canadian Human Rights Act, but they face discrimination, stigma, and violence in real-life contexts.

OUR FAILURE TO ACT IS AN ETHICAL FAILURE

Trans people need improved access to inclusive health and social services. We know what trans communities need, but we have failed to live up to our legal responsibility to ensure that trans people are included and welcomed in these services. We need to target the social determinants that fundamentally shape the health outcomes of trans communities, but we also need our health and social services to break their history of silence and come out as bold allies and advocates for trans people.

Our failure to act on trans inclusion is a gross violation of the health ethics at the core of our work. If we believe in the principles of “do no harm,” autonomy, and justice, we must admit that we have failed to enact these principles in our historic and present care for trans communities. Our continued failure to support and affirm trans people is an affront to the very ethics our services claim to live by.

We must marshal the political, economic, and social capital needed to fundamentally change our health and social services. We must also make trans inclusion a core value in all of our agencies and advocate for our provincial and federal governments to allocate funding and create strategies allowing us to move forward – not just as health and social service providers, but as a country – and do better for trans people.

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HOW DID YOU COME TO WORK ON THIS ISSUE?

I came to this work because of my personal experiences existing in this world, accessing services, and striving to survive as a trans person, and because of the violence and harm I see enacted on my community.

WHAT IS A GENDER-AFFIRMING CARE MODEL?

Gender-affirming care can be understood as the processes through which a health care system (or other types of health and social services) cares for and supports trans people by respecting their sense of self and chosen gender expression. By gender expression, we mean the way in which an individual chooses to express or display their gender. This could include things like choices of clothing, speech, or preferred names and pronouns. Most importantly, gender-affirming care recognizes that each individual expresses their self-described gender identity in unique ways and should be respected, cared for, and protected.

WHAT IS THE TRANS PULSE PROJECT?

Trans PULSE is a community-based research project designed to identify and respond to problems with health and social services faced by Ontario's trans communities. The research group collects data about these problems through a variety of methods, including focus groups, interviews, and surveys. Trans PULSE then uses this data to propose changes in policies and practices to help trans communities in Ontario and beyond.



TRANS PULSE
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ONTARIO'S TRANS
COMMUNITIES.

ETHICAL IMPLICATIONS OF ENGAGING PATIENTS IN RESEARCH: WHAT ARE WE MISSING?

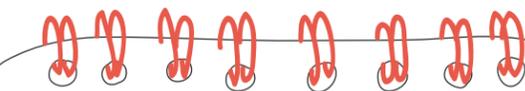


JENNIFER JOHANNESSEN (MSC BIOETHICS) is an independent healthcare consultant and educator with a particular interest in fostering critical reflexivity in clinical practice.

In recent years, enthusiasm for patient engagement – where patients (and caregivers) are enrolled by healthcare institutions to participate in a wide range of non-clinical activities – has found its way into health research, with the inclusion of patients as research “partners.” Patients, working in collaboration with researchers, now help set research priorities, develop research questions, contribute to research design, participate in data analysis and synthesis, and help disseminate results. This popular

trend is reinforced by the Canadian Institute of Health Research’s Strategy for Patient Oriented Research, which outlines a mandate to include patients at all levels of health research.

For many, the inclusion of patients in research appears unproblematic. Indeed, for some, the “patient voice” has been missing from healthcare planning and decision-making for too long, and patient engagement seems an obvious solution. The need to include patients as partners is often deemed a foregone conclusion, which may explain why patient engagement does not seem to be raising concerns in the field of health ethics in Canada. However, I think that this may prove to be a regrettable oversight: the practice of patient engagement is fundamentally changing how we think about and conduct health research, the impact of which has unknown consequences for both patient well-being and health research integrity. As patient engagement programs forge ahead with uncritical and enthusiastic support, health ethics needs to consider the risks and potential harms of such programs.



HOW DID YOU COME TO WORK ON THIS ISSUE?

As a parent to a child with multiple severe disabilities, I have spent decades as an enthusiastic “engaged patient.” Recent observations and reflections, along with my bioethics training, have however cast patient engagement in a different light. My goal is to investigate our healthcare-related values and ideologies (including patient engagement) through a critical lens, to help discover what else might be going on beyond our taken-for-granted assumptions.

A GRAND SOCIAL EXPERIMENT

The suggested benefits of partnerships between patients and researchers – such as claims that co-produced research is more relevant to patients or that engaging in a collaborative process is empowering for patients – are not well supported in the literature. Despite this lack of evidence, patient engagement in health research is quickly growing into a robust and self-sustaining industry. It now has its own terminology, professional associations, methodological frameworks, and training and certification programs for patients. Funding agencies often require or strongly suggest the inclusion of patient engagement activities on applications.

In all areas of healthcare where patient engagement is taking place, researchers are actively discussing the best ways to recruit and support patients in their new role as collaborators – and reasonably so: patient engagement is a grand social experiment, and the involvement of patients in activities previously reserved for professionals disrupts the traditional nature of patient-healthcare provider relationships.

THE BIGGER PICTURE: WHAT ARE THE RISKS AND POTENTIAL HARMS?

Broader ethical questions start to appear when we zoom out. As a starting point, think of the fact that engaged patients are self-selected volunteers, often with pre-existing friendly relationships with the researchers with whom they partner. They are unelected, unknown to the wider patient population, and not necessarily representative of interests unfamiliar to them. What’s more, the exact purpose of their participation is rarely specified.

As research partners, these patients weigh in on matters that might deeply alter the trajectory of research projects. Indeed, many researchers recognize that engaged patients can influence projects in unanticipated ways. While some may see this as evidence of a successful partnership, as ethics professionals, we must recognize the risks and potential harms in this freeform approach to involving patients in health research. For example,

since protections for patients as research subjects do not apply to patients in their role as research partners, there is no recourse or mechanism for redress if patient partners experience malpractice or harm.

Health research is governed by its rigorous adherence to ethical review and oversight, and the integrity of research methodology is paramount to its credibility. Yet, claims of improved health outcomes or relevancy because of patient engagement remain unproven. Instead, relationships between patients and researchers in this context are undefined and without clear boundaries, and the influence of patients is still poorly understood.

A SIGN OF THE TIMES?

It may be no coincidence that patient engagement is gaining momentum at a time when the political climate is one of rising populism, anti-science sentiment, and increasing pressure for market-based healthcare and “relevant” health research. Perhaps patient engagement, bolstered by its strong and vocal support from patients, is an inevitable outcome of these converging trends. We would do well to develop a much better understanding of how engaging patients in this way impacts the very nature of health research before we continue to invest in the future of such partnerships.

A SCENARIO OF PATIENT ENGAGEMENT

Dr. Z wants to apply for a research grant to investigate heart disease in pregnancy. Although she hasn’t done this before, she thinks it’s a good idea to include patients in the research process as partners or advisors and decides to form a Patient Advisory Committee for this research project. She invites a recent patient who previously expressed an interest in research and who had a positive treatment outcome. That patient knows two other patients who might like to help, and they also are invited. To round out the committee, Dr. Z contacts the Communications department at her hospital, which keeps a list of trained volunteers. Dr. Z now has a small committee of patients to advise on various aspects of the research project. However, Dr. Z is uncertain of how she should proceed with her new group of inexperienced advisors.

WILL AN APP A DAY KEEP THE DOCTOR AWAY?

MA'N H. ZAWATI (DCL) is the Executive Director of the Centre of Genomics and Policy at McGill University.



available to the public. Indeed, there are at least 100,000 of them currently in circulation, giving millions of consumers easy access to health information, symptom management tools, and diagnostic predictions. In 2025, the overall digital health market is expected to exceed 500 billion dollars in revenue.

In Canada, there is a lack of thorough ethical guidance on the use of mobile health applications, leaving users without any standards by which to distinguish effective applications from marketing hype. This is why I believe they have become the most pressing and timely challenge in Canadian healthcare ethics today.

MOBILE HEALTH APPS: A QUICK CATEGORIZATION

Mobile health apps are not monolithic. They can generally be classified into five major categories: (1) general health and wellness information applications; (2) illness prevention and management applications; (3) tracking, logging, and trending applications; (4) association applications; and (5) research applications. The first three categories, as currently envisaged, do not pose major health risks to the public (setting aside more general privacy and data security concerns). This is not the case, however,

In principle, the answer to this question should be no. However, with mobile health applications (applications developed on mobile devices to collect, store, and share health information) quickly proliferating on digital platforms, the answer to this question must be nuanced to account for the increasing variety of existing smartphone tools

for association applications, which could lead to direct health risks if not properly regulated.

THE CASE OF ASSOCIATION APPLICATIONS

Association applications provide the user with checklists of common symptoms and associate them with lists of possible medical conditions. Selecting 'fever' and 'muscle aches' on the list of symptoms, for example, may suggest cases of influenza, meningitis, and a range of other worrying disorders. For such applications, the potential harms are momentous: without proper consent standards, consumers (and potentially symptomatic patients) may misunderstand the purposes and limitations of these applications. Applications that collect and store data may not have clear privacy policies and may access or share user information without protecting confidentiality. Perhaps most importantly, the content of applications that associate symptoms with disease may lack validation for clinical accuracy. Recently, a study has shown that 3 out of 4 smartphone apps "incorrectly diagnosed more than 30% of cases of melanoma as being benign" (1). For a digital health care provision system to succeed, diagnosis cannot be this unreliable. Furthermore, if we would like patients to receive consultations through applications and other forms of e-tools in the future, we will need proactive and anticipatory guidance.

In April 2018, Health Canada signaled its intention to consider regulating digital health technologies, including mobile health apps. At the end of January 2019, a draft Guidance established that the Food and Drugs Act and its Regulations would cover any application or other software meeting the definition of 'medical device'. That said, software that matches patient symptoms with treatment guidelines for common illnesses, for example, will not meet the definition of a medical device – which means the ethical challenges and dangers of association apps remain not fully addressed for the average Canadian app user and health technology consumer.

SOME POTENTIAL SOLUTIONS: BETTER GUIDELINES AND EDUCATION

While Health Canada's draft Guidance is a positive development, it is unlikely that federal regulation will be capable of giving sufficient oversight of this rapidly developing field. What we need is a concerted effort by regulators, along with professional colleges and consumer protection agencies, to develop proper guidance. This type of guidance should not be limited to legislations protecting the public; it can also include soft law instruments (in the form of statements, guidelines, opinions), which could then be disseminated among specific audiences (physicians, etc.). More specifically, guidelines for using mobile apps in clinical practice and for recommending them to patients should be developed and periodically revised. Specific limitations on what an app can or cannot do should be clarified.

Furthermore, training the next generation of physicians to use these tools will also be crucial. Medical programs in Canada will need to include both mobile and digital health considerations. In fact, the traditional duties of physicians, such as the duty to inform or the duty to uphold professional secrecy, will all be affected by the arrival of these new technologies in the clinical setting. By acquainting medical students with these issues, students will be better equipped to recommend credible applications in the future and assess the needs of their smartphone-wielding patients.

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MICHÈLE STANTON-JEAN

a travaillé plusieurs années comme sous-ministre de la Santé au gouvernement fédéral et est maintenant chercheure invitée au Centre de recherche en droit public. Elle est aussi membre du Comité stratégique d'implantation du Plan d'action régional intégré (PARI) en santé publique pour la participation sociale des aînés.

« ET NOUS SOMMES ENTRÉS PAR CONSÉQUENT DANS UNE PÉRIODE EN RUPTURE TOTALE AVEC CE QUE L'ON A CONNU. CE N'EST PLUS LE MÊME HOMME, CE N'EST PLUS LA MÊME VIE, CE N'EST PLUS LA MÊME MORT, CE N'EST PLUS LE MÊME ESPACE, CE NE SONT PLUS LES MÊMES RELATIONS ».

MICHEL SERRES

VIEILLISSEMENT DE LA SOCIÉTÉ : UNE RÉFLEXION BASÉE SUR L'EXPÉRIENCE

Les données du recensement de 2016 de Statistiques Canada dressent le portrait d'une population dont le vieillissement s'accélère à mesure que les bébés boomers atteignent 65 ans et quittent le marché du travail. Selon ce recensement, plus du quart de la population canadienne aura plus de 65 ans en 2031. Ce constat est lourd d'implications pour le domaine de la santé.

UN DÉFI PRATIQUE : QUE FAIRE DES PERSONNES ÂGÉES ?

À l'heure actuelle, au plan de l'éthique pratique, l'une des questions les plus difficiles à traiter en santé publique et en soins de santé est celle du vieillissement de la population : comment penser et redéfinir nos pratiques en matière de vieillissement, ou encore, que faire des personnes âgées ?

Faudrait-il les isoler dans des maisons de retraite? Les inciter à mourir le plus vite possible afin de diminuer les coûts des soins de santé? Ou encore les considérer comme une richesse et un apport important dans la construction d'un meilleur système de gestion des institutions sociales et médicales liées à la santé? Ces «vieux», que nous ne voulons plus nommer

vieux mais personnes âgées, aînés ou autres qualificatifs, ont financé par leurs impôts nos systèmes de santé et d'éducation et nos services collectifs. Ils ont souvent travaillé sans accumuler de retraites confortables et se sont dévoués pour faire éduquer leurs enfants et leur procurer un avenir plus confortable que le leur. Ils ont donc mérité qu'on s'occupe d'eux. Malheureusement, nos infrastructures et nos services sociaux et sanitaires ne sont pas toujours adaptées à leurs besoins, notamment parce que ces personnes souhaitent majoritairement demeurer à la maison. De plus, les ressources humaines et financières qui leur sont dédiées sont insuffisantes.

Ce contexte fait en sorte que les principes, valeurs et cadres éthiques définis au cours des dernières décennies du XX^{ème} siècle sont souvent bafoués. La dignité humaine, la solidarité, l'équité, l'humanisme, le consentement, l'universalisme et le partage des bienfaits de la science sont mis à mal par le protectionnisme et le libéralisme économique. L'approche comptable de nos modèles de gestion est à mille lieues de l'éthique narrative et de la démocratie participative, deux pratiques qui demandent formation, écoute de l'autre, temps et patience, des éléments dont les personnes âgées ont particulièrement besoin.

QUELQUES PISTES DE TRAVAIL POUR PENSER « EN DEHORS DE LA BOÎTE »

Parmi les pays du G7, le Canada présente la deuxième plus faible proportion de personnes âgées de 65 ans et plus (17,2 %) après les États-Unis (15 %) (2). Nous avons donc encore un peu de temps pour repenser notre responsabilité face à une population vieillissante et pour réfléchir « en dehors de la boîte », comme nous y convie Michel Serres dans l'extrait cité en exergue.

Comment ? Il faudrait d'abord repenser notre définition de la vieillesse, qui ne commence plus à 65 ans. En effet, les frontières du vieillissement actif se sont déplacées grâce à l'amélioration des habitudes de vie. Comme le font déjà plusieurs pays, il faut innover en matière de gestion de la main d'œuvre et mettre en place des pratiques qui permettent à ceux qui le souhaitent de demeurer plus longtemps au travail. Il faut aussi continuer des recherches qui impliquent à la fois et dès le départ des chercheurs en sciences de la santé, mais aussi des chercheurs en sciences humaines et sociales et des personnes âgées, afin d'impliquer tous ces acteurs dans l'élaboration de projets et de politiques liés aux aînés. Il est aussi essentiel d'évaluer les impacts réels de leur mise en œuvre. Si ces processus reposent uniquement sur des objectifs de gestion quantitatifs, ils ne contribueront pas à identifier comment diminuer la marginalisation et l'isolement des personnes âgées.

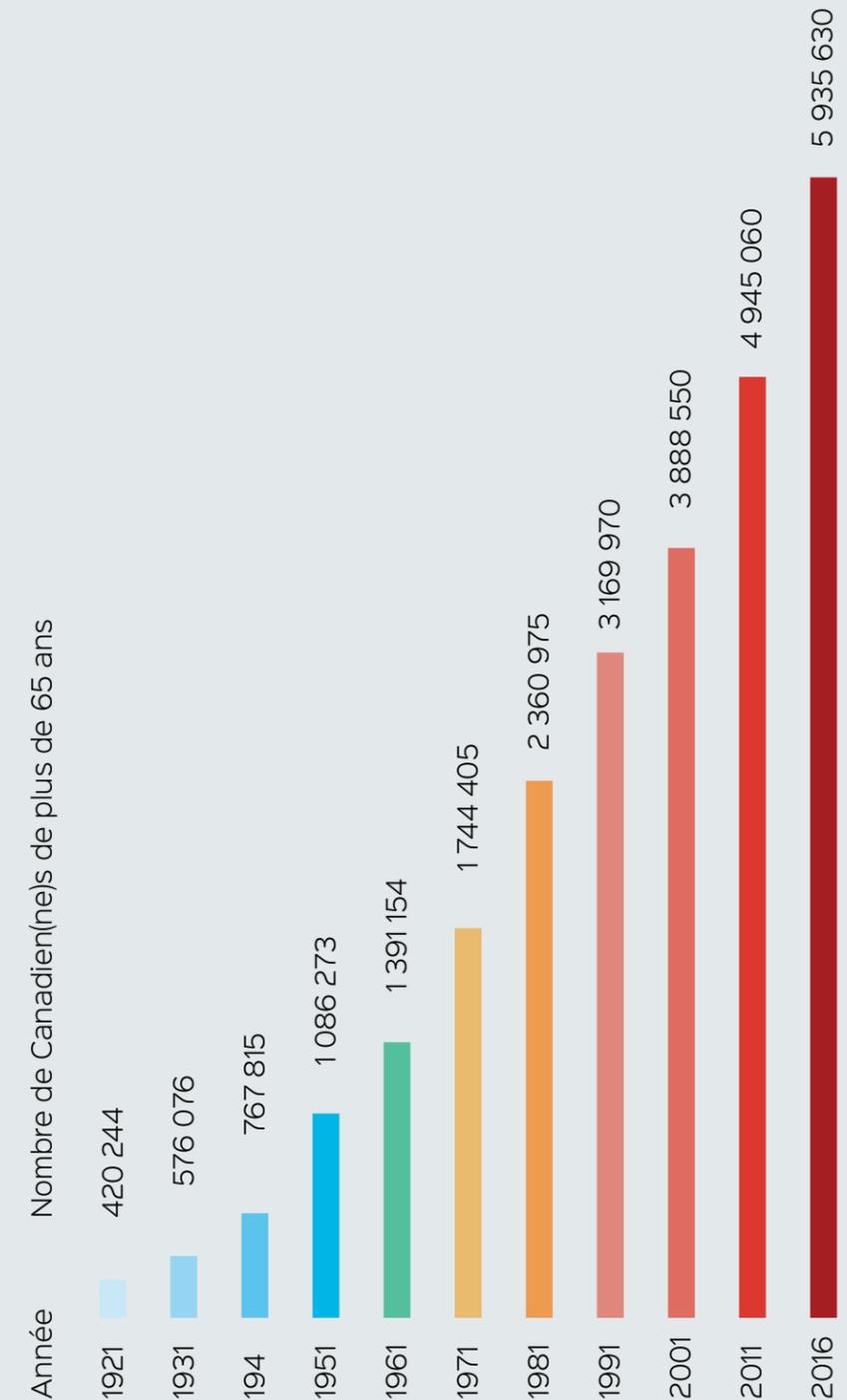
Les aînés sont des acteurs et non de simples spectateurs dans notre société : « [Ils] détiennent [...] un potentiel et des expertises prêtes à servir au bien commun, pour autant qu'on leur en donne les moyens » (3). Une telle vision de cette période de la vie devrait être le moteur de nos actions dans ce domaine.

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COMMENT EN ÊTES-VOUS VENUE À TRAVAILLER SUR CETTE QUESTION ?

J'ai commencé à m'intéresser à cette question lorsque, à la faculté des études supérieures de l'Université de Montréal, j'ai coordonné l'élaboration d'un programme appelé Vieillesse, santé et société. J'ai ensuite donné un cours dans ce programme sur l'histoire du vieillissement, en 2008. Ensuite, je n'ai jamais cessé de suivre les politiques publiques et les recherches sur cette question.



Source du graphique

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WHY SHOULD WE CARE ABOUT LANGUAGE BARRIERS IN HEALTH CARE?

Many people in Canada may face barriers in accessing appropriate health care because they are not fluent in one of the official languages. Almost 23% of Canadians report a mother tongue other than English or French, and 21.8% speak one of these other languages at home (1).

In Canada, official language minorities (English speakers in Quebec and francophones in most of the rest of Canada), speakers of Indigenous languages, immigrants whose first language is neither English nor French, and users

of sign (visual) languages all face potential challenges in accessing health care. In spite of differences between these groups, all patients who experience language barriers face similar risks and similar ethical issues. These ethical issues include equitable access to services, equitable distribution of resources, protection of vulnerable persons, respect for patient choice, and patient privacy and confidentiality.

The rights of these individuals to receive services in their preferred language varies, as does the availability of services to assist them in communicating with health providers. However, the risks that patients face when they face language barriers, and the ensuing ethical issues, are similar. Language barriers create important ethical, social, and clinical problems for people receiving care and for the Canadian health care system more broadly.

A RISK FOR PATIENTS AND A RISK FOR THE HEALTH CARE SYSTEM

We know from both Canadian and international research that not addressing language barriers can pose serious risks to quality of care and patient safety (2). People who are not fluent in the dominant language are often unable to participate in health promotion initiatives or preventive care. This increases the challenges they face in staying healthy. When they seek care, language barriers mean they are less likely to get an accurate diagnosis and receive the most appropriate treatment. They are less likely to understand the treatment that their health care provider is recommending or instructions for medication use or follow-up care. This means that often, they may not obtain the full benefit of medications or other treatments prescribed to them. Because they do not understand consent forms, they may also undergo procedures that they do not want.

There are also risks to health care providers and to the health system itself. Because of language barriers, providers may be less confident in their diagnosis, and errors due to misdiagnosis may increase risks of provider and organizational liability. When there is a language barrier, health providers often act more cautiously with patients. For example, they may order additional tests or extend a hospital stay. When patients are misdiagnosed, or do not feel their concern is understood, they may make multiple visits for the same problem. In these ways, failing to address language barriers may result in inefficient use of health care resources, a particular concern at a time when our health care system is under stress.

When patients cannot completely understand the treatments and alternatives offered to them, they are unable to give informed consent: failing to meet this ethical requirement not only subjects patients to procedures they may not agree to, but also poses a risk to the health system.

LOST IN TRANSLATION: LANGUAGE ACCESS SERVICES FOR VULNERABLE PATIENTS

We can address these ethical concerns by providing trained and confidential interpretation services in cases where health care services are not available in the patient's preferred language. Unfortunately, in Canada, such services are often not used, nor even readily available. Untrained individuals, such as family members, acquaintances, or passers-by are often called on to provide language interpretation. This response fails to protect the patient's right to privacy and confidentiality, as there are no guarantees that the individual asked to perform the role of interpreter will not share private medical information. Using untrained interpreters also fails to protect against other ethical failures, as these individuals often lack the skills to accurately convey the communication between the patient and care provider.

Canadians take pride in their commitment to protecting the most vulnerable. Many individuals who face language barriers are also members of groups who are vulnerable due to other factors, such as poverty, racism, discrimination, or historical trauma. For example, many refugees arrive with trauma-related physical and mental health concerns. Failing to address communication barriers to appropriate health services can exacerbate the stress of settling into a new country and can even create new problems. As another example, as people age, they often lose their ability to speak and understand their second language fluently. As the Canadian population ages, we will find that many seniors who have lived and worked for most of their lives speaking English or French may be increasingly unable to communicate well in their second language and so face communication challenges they had not faced before. For this reason, issues related to language barriers - far from disappearing - will continue to pose ethics challenges in Canadian health care in the future.

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