

Challenges facing Indigenous transplant patients living in Canada: exploring equity and utility in organ transplantation decision-making

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ABSTRACT

Indigenous peoples in Canada and in the Circumpolar North face a higher disease burden leading to end-stage organ failure and face geographic and systemic barriers to accessing health-care services, including those for end-stage organ failure and organ donation and transplantation (ODT). To address these issues, I present a think tank model used in Saskatchewan, Canada, which focused on ODT and recommended research and policy changes that address inequitable Indigenous access to ODT, most specifically in northern and remote regions. Over the past three years, think tank members, comprised of Indigenous cultural leaders, elders, and persons with lived experience in ODT, and complemented by medical and advocacy experts, have highlighted equity and utility issues as key concerns, and discussed ways in which these issues can be addressed. Recommendations include culturally-safe methods for documenting and tracking Indigenous identity, development of training to address culturally specific needs, and additional funding to support Indigenous transplant donors and recipients.

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Introduction

First Nations, Inuit, and Métis peoples carry a heavier burden of chronic disease and associated risk factors than the broader Canadian population, with rates of diabetes, autoimmune and viral hepatitis being particularly elevated [1–3]. Compounding determinants such as housing, food and water insecurities, high unemployment, and poverty negatively contribute to health disparities and inequities across all three Indigenous groups [3–5]. Northern, remote, and rural Indigenous populations are further challenged as small population sizes mean that there are significantly fewer local diagnostic and health-care services, and the distances to travel to receive these services is often challenging for patients and families, particularly when regular treatments are required [1,5–8].

The following discussion examines Indigenous peoples and healthcare equity as it relates to end-stage organ failure, and organ donation and transplantation (ODT) in Canada. The heavier burden of illness experienced by Métis, First Nations and Inuit populations directly contributes to elevated rates of end-stage organ failure, where the preferred treatment is an organ transplant [5,9,10]. The following analysis draws attention to the challenges faced by Indigenous health-care leaders and providers, people living with end-stage organ failure, and the families and caregivers who support them. The goal of

the discussion is to provide insight and direction generated by Indigenous people about ODT to inform Indigenous health-care leaders and ODT decision-makers tasked with improving ODT systems across Canada, and internationally.

Saskatchewan First Nations and Métis organ donation and transplantation network

In April 2019, the Saskatchewan First Nations and Métis Organ Donation and Transplantation Network was formed. The Network is designed as an Indigenous “think tank” that bridges Indigenous, biomedical, health-care services, policy, legal and research interests in ODT. It consists of Indigenous people with lived experience (transplant recipients, living donors, family members), Elders, Knowledge Keepers, Indigenous researchers and students, and non-Indigenous medical, legal, and research experts. The Network meets monthly for four hours, with an agenda including one or two presentations from either an Indigenous person with lived experience of ODT or a professional ODT expert. The meetings, which moved to an online format in March 2020 due to COVID-19 restrictions, are designed to be productive and safe spaces for collective knowledge generation. The Network generates knowledge by supporting dialogue and debate

from different professional, cultural, and lived experience vantage points, with topic areas being revisited multiple times across meetings as new experts are invited to participate.

People with lived experience and Indigenous Knowledge Keepers are key to the Network's value. These individuals directly address the importance of including Indigenous knowledge, languages and practices in health-care policies, planning and delivery. Their firsthand experiences navigating the healthcare system as patients, as health-care providers, and/or as cultural experts are key to understanding experiential intersections, such as the relationship between health inequities and historical and contemporary oppression of Indigenous peoples. Lived experience narratives are shared at monthly Network meetings as well as at public events and webinars hosted by the Network. Voices of those with lived experience are amplified because of the Network's format and regular meetings, and because of the value placed by the Network on patient and family narratives about their illness and analysis of their health-care journey. The contributions of people with lived experience bring valuable insight and information to inform Indigenous people who want to learn more about ODT. Additionally, lived experience narratives are powerful, and effective knowledge translation tools to educate non-Indigenous ODT decision-makers and experts in the absence of published ODT information generated by and with First Nations, Métis, and Inuit peoples.

The Network's research program feeds into the monthly think tank meetings, with updates given at each meeting. Findings are discussed with Network members and invited experts. The Network currently holds two research grants: one focused on Indigenous peoples and living donation; and the other on Métis and First Nations perspectives of ODT, as described in the funding section at the end of this paper. The think tank discussions add greatly to the interpretation and analysis of the data, as well as to the educational value for Network members and guests. Published works are purposely written in accessible language for a wider audience. An unexpected outcome of participant recruitment for the research studies is that Indigenous patients and families are reaching out to the Network for information and support.

At the end of 2020, the Network expanded its reach to establish an international arm, which includes Indigenous and non-Indigenous experts from Aotearoa-New Zealand and Australia, with plans to establish similar relationships in 2022 in Circumpolar countries. The inclusion of international perspectives highlights similar challenges faced by Indigenous peoples across

different countries, and the partnerships also provide for sharing of valuable information about Indigenous-designed and -implemented ODT initiatives, Indigenous ODT health improvement strategies, and research programs. While the international arm is in its infancy, several activities are planned, including an international collaboration that intersects Indigenous perspectives with cross-country comparisons of ODT policies, research, and service provision.

By January 2022, nine Indigenous experts with lived experience of ODT, 12 ODT medical experts and 14 policy and advocacy experts had presented or joined one or more of the Network meetings. The Network's online meetings are open to expert visitors, both those who have previously presented, and experts interested in learning about the Network. Our inclusive approach adds to the depth and complexity of discussion and analysis that occurs at each meeting. The research leads also meet regularly with other researchers who have expressed interest in forming partnerships with the Network. Research members of the Network participate in a Health Canada initiative to improve the national ODT system[11]; however, this initiative does not include Indigenous health-care leaders from First Nations, Métis, and Inuit governments or organisations, a criticism brought forward by Network participants. Increasingly, the Network is called upon by Indigenous leadership, provincial and national governments, and non-governmental agencies for advice on ODT issues relevant to Indigenous peoples. Network researchers and staff maintain a regularly-updated literature review, media reports, and analyses of the knowledge generated in the monthly meetings, bringing this back to the think tank for further discussion and debate.

What is clear from the Network's engagement work is the desire of Indigenous peoples to have more information about ODT and to be involved in ODT decision-making. This, I contend, begins with greater inclusion by provincial/territorial and national ODT decision-makers of Indigenous health-care leaders, persons with lived experience, and key experts. Canada's ODT decision-makers are almost exclusively located in large urban-based hospitals, government ministries, organisations, and universities, and most have a limited understanding of the degree and nature of equity issues specific to Inuit, Métis, and First Nations peoples. The emergence of an Indigenous network focused on ODT in Canada, despite our current funding and capacity limitations, is an initial step in bringing the voices of Indigenous peoples to ODT decision-making. In the following analysis, I draw attention to key areas where strategic partnerships and collaboration could be formed, including across Circumpolar countries, with

the goal of increasing Indigenous participation in ODT discussions and decision-making, and to improving access and quality of care for Indigenous patients.

Understanding equity and utility intersections in providing ODT services

In delivering ODT services across Canada, ensuring equitable access to organs for patients who require a transplant is a desirable but challenging goal. Equity is somewhat addressed through coordination of national registries operated by Canadian Blood Services (CBS) and inter-provincial agreements between provinces and transplant programs, but there are still shortfalls in the number of donors versus the number of people in need[5]. In 2020, there were 734 deceased organ donors and 487 living organ donors in Canada, who provided organs to 2,622 patients. Canada has a shortage of organs, with 4,129 patients in 2020 waiting for transplants at the end of the year, and 276 Canadians who were waiting on a transplant list dying, up from 250 to 223 in previous years. [12]

A shortage of organs means that decisions about organ allocation inevitably involve weighing issues of equity – all transplant patients across Canada have equal access to organs – with questions of utility – given the shortage of organs, each organ should be transplanted into the recipient with whom it will survive the longest[13]. A utilitarian approach considers intersecting factors such as: the patient’s age (e.g. how heavily should the respective ages of the donor and recipient be considered when deciding which patient receives an available organ?); existing comorbidities (e.g. how heavily should existing comorbidities be weighted when deciding if a patient should be placed on a transplant list or when organ allocation is being made?); other health risks (e.g. how heavily should “lifestyle” risks be weighted, such as substance use or obesity?); and patient compliance (e.g. if a transplant patient does not comply with assessment and workup regimes, for whatever reason, how heavily should this be weighted in organ allocation?).

An equity approach takes into consideration how to reduce factors that negatively impact a transplant patient’s chances of receiving an organ. These include factors such as: geographical location (e.g. does the place where someone lives prevent them from having full access to ODT services?); ancestry/ethnicity (e.g. are patients from certain ethnic groups excluded or removed more often from transplant lists or do they wait longer for a transplant than patients from other ethnic groups?); immunological barriers (e.g. are immunocompromised patients, such as HIV- positive patients,

less likely to receive a transplant?); the ability of a patient/family to cover associated costs (e.g. do expenses such as travel, lodging, and loss of income prevent some patients from having full access to ODT services?); and compounding bias (e.g. are some patients disadvantaged because of compounding factors such as where they live, their gender, age, ethnicity and socioeconomic status?). These decisions may be made within allocation schemes that lead to certain patient populations being left off or removed more often from the transplant wait list, waiting longer to receive an organ than other patient populations, or receiving suboptimal organs.

In the allocation of organs, patient/donor compatibility, equity, and utility considerations are simultaneously weighed when transplant programs are making their decisions. To ensure equity, health authorities and transplant programs have policies and procedures in place to guide decision-making. However, these decisions are balanced by the transplant team with utilitarian considerations that present at the time of decision-making. Other medical considerations, such as the compatibility of recipients with donors, and living donors giving organs to specific patient recipients, are also factors that weigh into the allocation of organs. While it is impossible to know exactly how all considerations are weighted when decisions are made about which patients receive which organs, there are ways to monitor the equity of outcomes of these decisions. For example, tracking of organ allocation by ethnicity, in this case, First Nations, Métis and Inuit identity, could provide an avenue of inquiry whether Indigenous patients are, or are not, lingering longer or dying more frequently on transplant wait lists than other groups. If it is known that Indigenous patients, or one group of Indigenous patients, such as First Nations, are lingering longer or dying more frequently on transplant lists, this, in turn, could generate further inquiry into why this is so, and if this finding is more prevalent in some regions of the country than it is in others.

Understanding the weighting of equity and utilitarian considerations by transplant teams at the time of organ allocation is important when considering the experience of Indigenous ODT patients. However, there is no existing data in Canada to draw upon that would determine whether Indigenous patients are or are not disadvantaged in organ allocation. At the same time, a multitude of factors are at play in the lives of Indigenous patients that are likely to diminish their chances of even being placed on a transplant list or being allocated an organ pre-emptively or even during the optimal window of time when a transplant would have the greatest chance of success [4,5]. The

remainder of this discussion focuses on relevant equity and utility issues for Indigenous patients who require a transplant. I begin by considering the ODT data gap that exists around Indigenous patients, and then discuss how this data gap potentially masks specific intersecting ODT equity and utility issues that are likely placing Indigenous patients at a disadvantage to receive organ transplants. I then offer directions on how ODT research and health-care services can be improved to reduce the inequities experienced by Indigenous patients and their families. I end by considering the value in establishing partnerships and collaborations across the Circumpolar North and the opportunities for Indigenous peoples to learn from one another about strategies for supporting northern patients living with end-stage organ failure and in need of an organ transplant.

The invisibility of Indigenous peoples in ODT data

A paucity of data about any health issue impacting Indigenous populations generally translates into systemic inaction on the part of Ministries of Health and health-care decision-makers. Presently, health-care decision-makers have limited data on the number of First Nations, Métis or Inuit patients living with end-stage organ failure or how many of these patients are on transplant wait lists[14]. Additionally, there is no way to track the number of First Nations, Métis or Inuit patients who are being excluded from transplant wait lists and the reasons why they are excluded; the number who receive transplants annually; the number who die while waiting for a transplant; the number of Indigenous patients who miss the optimal window of time when a transplant is likely to be most successful; or the average number of years of post-transplant survival. Without this data, Indigenous health-care leaders and provincial/territorial and federal health ministries, along with ODT decision-makers, have no way of knowing if, and when First Nations, Métis, or Inuit are over- or underrepresented in these patient populations.

End-stage organ failure and ODT also receive limited attention from Indigenous health-care leaders. This is largely due to population-level health issues, such as suicide, HIV, diabetes, addictions, cancer, heart disease, mental health, and more recently COVID-19, being more demanding of attention. While many of these health problems directly contribute to end-stage organ failure, this has not translated into their targeted attention to the needs of Indigenous patients where the preferred treatment is transplantation. Additionally, investment by provincial/territorial and federal

governments to support Indigenous health-care leaders and experts to be involved in decision-making about ODT governance, data management, research, and care delivery is limited. The lack of involvement of Indigenous healthcare leadership in these discussions means tracking of ODT data by Indigenous identities, and determination of the unique challenges facing Indigenous patients and families, are less likely to be documented and fully understood.

Significant and important cultural, linguistic, geographical, jurisdictional, and equity differences exist between and within First Nations, Inuit, and Métis nations that require ODT data to be collected and analysed using a distinctions-based approach (looking independently at the three groups, and subgroups within). This approach ensures that the distinctive and respective rights, interests, and circumstances of First Nations, Métis and Inuit nations are acknowledged, and, with input from Indigenous health leaders and experts, inform ODT decision-making. Indigenous leaders rely on distinctions-based data when engaging with governments and other stakeholders about healthcare reform, resourcing, and service delivery targeting their respective populations. Along with Indigenous health-care leaders and service providers, Indigenous patients and families are best situated to provide direction to ODT decision-makers. Inclusion of researchers with expertise in Indigenous health care equity also brings key information and analysis to the discussion.

Documentation of First Nations, Inuit and Métis identity is excluded in most health administration and utilisation data, which can become particularly problematic when Indigenous patients travel across jurisdictional lines; for example, when Inuit, Métis, or First Nations patients travel from a Northern Territory to a southern provincial hospital. Status First Nations and Inuit patients who cross jurisdictional lines can be tracked because they have a status number registered under the Indian Act of Canada, since it is provided when they receive health-care services. Otherwise, unless another form of tracking is in place, no record of a patient's Indigenous identity is recorded across jurisdictional lines. Because provincial transplant programs do not coordinate data collection across jurisdictions, there is currently no way for Indigenous health leaders to know the number of Indigenous patients travelling across jurisdictions, or the specific health-care services they are, or are not, receiving. Postal codes and geographical region can be used as surrogate identifiers of Indigenous identity in regions where Indigenous people make up the large majority of the population (e.g. northern provincial regions and northern territories); however, this data captures all people living in

catchment areas and distinct Indigenous identities cannot be determined.

To date, Indigenous groups have experienced limited success in entrenching their research and data sovereignty principles into bodies that collect and analyse health administrative and utilisation data in the different provincial and territorial jurisdictions. For the most part, decision-makers who control these data have been reluctant to engage in discussions with Indigenous leaders to establish Indigenous data-sovereignty and data sharing agreements. As a result, there is limited movement to establish a distinctions-based approach to collecting and analysing health administration and utilisation data that records and tracks Métis, First Nations, and Inuit patients.

As ODT decision-makers seek to improve ODT systems of care nationally, a notable shortcoming is the lack of data about Inuit, Métis, and First Nations patients at risk of, or living with, end-stage organ failure. The unique circumstances and challenges experienced by Indigenous peoples living in northern, remote and rural areas, or of those Indigenous individuals experiencing compounding health disparities in all geographical regions of Canada, is largely absent from discussions about improvements to ODT programs and systems[5]. While limited, existing evidence points towards Indigenous populations not only being at elevated risk of experiencing end-stage organ failure due to co-morbidities, such as diabetes, viral hepatitis, alcoholism, and obesity[15], but also that the onset of end-stage organ failure occurs at earlier ages[16], advances more rapidly[17], and Indigenous patients, even children, wait longer on transplant lists and are less likely to receive a transplant from a deceased or living donor [5,18,19]. However, research is emerging that suggests Métis, at least in some regions of the country, experience kidney disease at similar or slightly higher rates to non-Indigenous Canadians, even in northern regions [20]. Due to a lack of Métis-specific data, the assumption is that rates of kidney disease leading to end-stage organ failure are similar between Métis, First Nations, and Inuit. Requiring distinctions-based data collection across regions of the country prevents blanket assumptions being made about Indigenous groups (within and across groups), offering important avenues for comparison and investigation of how underlying determinants contribute to health outcomes.

Intersections of equity and utility

In Canada, provinces and territories hold differing capacities for organ retrieval and transplantation. In the regions with the highest concentrations of Indigenous

peoples – northern, rural, and remote – there are far fewer services to prevent and treat end-stage organ failure and very limited donation and transplantation services. Currently, the northern territories (Yukon, Northwest Territories, Nunavut) have no organ donation, procurement, or transplantation programs (ODT). Patients in need of a transplant and living donors must travel to hospitals in southern urban centres for these procedures. Saskatchewan and Manitoba rely on other provinces to provide transplant services, except for kidneys. Nova Scotia provides services to the Atlantic region. While organ retrieval can occur in smaller provinces, most of these organs are transported to appropriate transplant hospitals in either Vancouver, Edmonton, Ottawa, London, Montreal, or Toronto. In the current context, those individuals living in remote and northern regions face a much harder struggle in accessing ODT services and are at a significant disadvantage relative to individuals living in large urban centres [5,7,15,18].

The demand for organs in Canada currently exceeds the number of available organs, and this gap is only increasing with time [21,22]. With differing provincial and territorial capacities to provide ODT services, ensuring equitable access to organs across the country is difficult. Coordination for ODT across provinces/territories occurs through national registries operated by Canadian Blood Services (CBS) and inter-provincial agreements between provinces and transplant programs. Three interprovincial organ sharing programs are operated by CBS, including the National Organ Waitlist (NOW), the Kidney Paired Donation (KPD) program and the Highly Sensitised Patient (HSP) program. CBS also maintains the Canadian Transplant Registry (CTR) web platform to assist in linking potential organ recipients with donor organs[23]. At the end of 2020, 4,129 patients were waiting for an organ transplant, with 2,622 people being on the active waiting lists for kidney, liver, heart, lung and pancreas transplants[11]. In 2020–21, the COVID –19 pandemic resulted in transplant services being suspended or limited for various periods of time in all parts of the country, reducing the number of transplants during this period[24]. COVID-19 lockdowns in remote and northern regions negatively impacted Indigenous patients seeking treatment for end-stage organ failure or donation/transplantation services, however the degree to which patients were impacted is unknown due to a lack of available data.

For First Nations, Métis, and Inuit patients who live in remote, northern and rural areas, travelling long distances or relocating to urban centres for long periods is often the only options for seeking the treatments they need for organ failure and to increase their

chances of a transplant[6]. In this context, numerous factors impact their decision-making about seeking treatment, including financial, family circumstances, transportation, employment, cultural and spiritual beliefs, and psychological/emotional factors[8]. The enormity of these challenges results in delayed access to treatments, patients foregoing certain treatments or patients simply not having the support or resources to seek the care they need[6]. In a narrative presented to our Network, a family living in the far north of Canada made the heartbreaking decision to give their young child up for adoption, so she could receive a heart transplant and live in a southern city near the aftercare support she required. The remoteness of their community meant that there were limited health-care services available, and as the family was unable to relocate, it was decided that adoption was the best option for the child's survival.

While this story is exceptional, it is an example of the unique and often insurmountable challenges faced by Indigenous peoples in healthcare decision-making – challenges that are not currently well captured in national ODT discussions. The additional complexity of seeking ODT diagnostic assessment, treatments, and services during the COVID-19 pandemic for people living in remote, northern, and rural areas has compounded the challenges, most likely resulting in increased morbidity and mortality rates among Indigenous people living with end-stage organ failure.

While First Nations and Inuit registered under the Indian Act can access certain supports from the Federal government's Non-Insured Health Benefits (NIHB) programme, such as medical transportation, travel and accommodation, these costs are not covered for Métis, or for non-registered First Nations or Inuit, as they access health-care services from provincial or territorial governments. The benefits received by registered First Nations and Inuit do not necessarily translate into local viable treatment options; instead, many patients under NIHB are relocated and housed in large, unfamiliar southern cities for treatment[6]. Patients covered by NIHB can, for example, find themselves living in hotels for months as they receive assessment or treatment in southern health-care facilities [25,26]. Residing in a small hotel room for extended periods (sometimes more than a year), eating restaurant food, being away from one's family, community, culture and supports, and lack of recreational/entertainment options, are contributors to poor mental, physical, and spiritual health [5,6].

For other Indigenous patients not covered by NIHB, relocation may not be financially feasible. Some, when possible, turn to family or friends who live in cities for

accommodation as they seek treatment. The stress of living far away from one's home and family, along with financial and other challenges, is extremely difficult for patients and families, some of whom have never lived in urban environments or away from their families and home communities. Additionally, Indigenous patients and their families may experience urban clinical and hospital settings as foreign and inhospitable environments that discriminate against and marginalise them [5,6,27].

Gaps and barriers in northern, rural, and remote local health-care services, such as a lack of dialysis treatment, greatly elevate the risk of rapid onset of end-stage organ failure and mortality among Indigenous peoples [4,8,15]. Even for Indigenous patients living in urban centres, the locations where they receive dialysis treatment can be far away from their homes, and some patients do not have appropriate and viable transportation options. Adverse experiences when seeking treatment for end-stage organ failure or when going through transplantation assessment are also a common and reoccurring theme reported to the Network by research participants and experts in Indigenous health. While not every person reports negative health-care experiences, examples given to our Network have ranged from narratives describing acts of overt racism to experiences where patients do not know if racism, an overwhelmed health-care unit and workers, or provider incompetence are most at play in how they were treated. In each example, however, Indigenous individuals who are living with serious and life-threatening conditions experience their conditions worsening because of negative or absent treatment. Indigenous patients and families also report feeling apprehensive about self-advocacy or having others advocate on their behalf during times when their needs are not being met. Fear of provider backlash, such as not being placed on the transplant list, being taken off the transplant list, having transplant testing and assessment withheld or stopped, and being overlooked as a recipient of a potential matching organ, are significant concerns impacting patient perceptions and experiences.

Transplant waitlists: equity, utility, and racism

When the preferred medical treatment is a transplant, patients are required to attend numerous medical workup appointments and extensive testing before they are approved to be on the transplant list. In the case of living donation, potential donors are also required to go through a series of screening and assessment procedures to determine their compatibility with

their transplant recipient and whether they have any health problems that exclude them as a donor. Workup and testing for recipients and donors occur over several months, requiring a significant commitment by each patient to the process. An important part of the transplant and donor assessment process is a subjective measure of medical “compliance” or “adherence”. Failing to attend appointments for procedures, such as X-rays or follow-up visits can be interpreted by health-care teams as patient “non-compliance”. Even when the circumstances causing a patient to miss appointments are known to be beyond the control of the patient, this can be interpreted as a sign that the patient might not adhere to post-transplant assessments and care regimes. Because Canadian health jurisdictions face an ever-present shortage of donor organs, non-compliance is high on the list of reasons not to include a patient on the transplant list, or to remove them from the list. Transplant programs are extremely sensitive to the risk of losing viable organs for transplantation and their subjective interpretation of a patient’s compliance is always at play.

Equity and utility considerations commonly run-up against one another in the context of transplant wait lists and organ allocation to Indigenous patients. For example, co-morbidities, perceived patient non-compliance, alcohol use, obesity, and being labelled a “difficult” patient, reduce the likelihood of a patient being placed on the transplant list. For Indigenous peoples, the intergenerational impacts of colonialism, including present-day manifestations of racism and prejudice, are also factors that can contribute to their exclusion from transplant wait lists [14,28]. At this time, however, it is simply unknown how frequently First Nations, Métis, or Inuit patients across Canada are denied access to transplant lists and the reasons why. Our research includes multiple narratives from Indigenous patients denied inclusion on transplant lists. In the narratives, patients and family members do not necessarily understand the reasons why access is denied, and they are inclined to either accept the decision of physicians without question and/or feel they have no power to change the minds of decision-makers.

A recent report, *In Plain Sight*, details the results of a review commissioned by the BC Ministry of Health. The review found widespread and entrenched racism across the BC health-care system[25]. The report states:

stereotypes of Indigenous patients being reluctant, mistrustful or non-compliant made them [study participants] reduce their efforts to reach out. Others [study participants] discussed situations in which healthcare providers failed to give appropriate information to

Indigenous patients, such as not properly explaining healthcare procedures or proceeding without informed consent. A number of submissions to the Review described being unable to contact Indigenous health liaisons and healthcare staff failing to advise them of complaint options and procedures. In Review submissions, patients spoke of various other ways in which they had been “shut out” of care – from being physically locked out of buildings, to being sent home without assessment, treatment, or planning, leaving them to make repeated attempts to access care. (p. 46)

The Circumpolar North and ODT

In seeking pathways to improve care for end-stage organ failure and ODT for Indigenous peoples in Canada, learning from the experiences of Indigenous peoples globally is key. The challenges faced by many First Nations, Métis and Inuit patients and their families are linked to where they live and the associated factors that contribute to gaps and barriers in diagnostic and health-care services. An opportunity exists to create cross-country dialogue between Indigenous groups in the Circumpolar North to come up with innovative ways to improve access to prevention, diagnosis, treatment, and aftercare support for patients at risk of, or living with, end-stage organ failure and who require organ transplants.

The Circumpolar North refers to “northern regions of countries in the arctic and subarctic regions that are either partially or completely located above the 60°N, including Canada, Denmark (Greenland and Faroe Islands), Finland, Iceland, Norway, Russia, Sweden and the USA (Alaska)”. [8] (p. 1) Despite differing health-care systems and levels of Indigenous self-governance over health care the Circumpolar North, Indigenous peoples experience similar challenges in accessing health-care services [8,29]. Huot and colleagues identify four intersecting themes characterising barriers to delivery of and access to health-care services across the Circumpolar region: influence of physical geography (distance to urban centres; weather and seasonal conditions; limited transportation options; travel and delivery costs), health-care provider-related barriers (staff shortages and high staff turnover; lack of training; varying professional knowledge, skills and clinical experience in treating specific medical conditions; professional isolation; and working in areas that are distant from urban centres), the importance of culture and language (communication/language barriers between patient and practitioner; health information that is not culturally-sensitive or relevant; health practitioners being unfamiliar with local Indigenous culture(s) and languages); and the impact of system factors (fragmented management

of healthcare delivery and access; lack of funding for health-care systems in northern communities; lack of appreciation by health-care providers and southern decision-makers about the constraints caused by low income, unemployment, high cost of necessities, and poor housing)[8]. Additionally, the lack of trust in health-care systems resulting from colonial histories of oppression and marginalisation exasperates the challenges.

Most notably in their scoping review, Huot and colleagues point out the overemphasis by southern researchers, policy, and other decision-makers that southern regions constitute the “norm” with the north presenting exceptional challenges that are not easily addressed or solved[8]. They write:

The heavy focus ... on challenges related to physical geography and climate reflect an emphasis on the difference from the southern regions as the norm (e.g. through the framing of communities as remote and isolated) and obscure the fact that, for Indigenous populations who have always lived there, this is their norm and healthcare was provided by local knowledge over thousands of years prior to colonization. For Indigenous peoples living in northern regions, the ability to access healthcare is linked with calls for Indigenous self-determination, whereby Indigenous peoples have rights to maintain traditional health practices, access public services and contribute to improving services according to their own priorities and values. (p. 6)

When considering challenges associated with patient care, end-stage organ failure, transplantation and living donation, Huot and colleagues emphasise engagement with Indigenous peoples living in the Circumpolar North because they know best what the local strengths and resources are that contribute to improved health outcomes and patient/family experiences. Identifying opportunities for northern and southern health-care decision-makers to explore and build local capacities that incorporate new approaches and technologies, such as the use of remote presence technologies, is key to improving health outcomes. The creation of a Circumpolar coalition focused on end-stage organ failure and ODT is an example of how Indigenous peoples living in the Circumpolar North could share their lived experiences, learn from one another, and collaborate on strategies and interventions specific to the northern context.

Conclusion and recommendations

Providing equitable access to diagnostics and treatment for end-stage organ failure and ODT to Indigenous populations across Canada is challenging. The multitude of factors negatively impacting the

ability of First Nations, Métis, and Inuit populations to successfully access diagnostic and treatment services highlights the need for significantly more resources to be directed towards health promotion and prevention of illnesses that are responsible for organ failure. Addressing equity further requires the specificity of First Nations, Métis, and Inuit identity when tracking data focused on end-stage organ failure, donation, and transplantation. Presently, health-care decision-makers have no way of knowing the number of First Nations, Métis or Inuit patients living with end-stage organ failure and how many of these patients are on transplant wait lists. In this context, specific data collection efforts that determine the number of patients in respective First Nations, Métis, and Inuit population who need a transplant but do not end up on the transplant list or do not receive an organ, and the reasons why, are vital to understanding equity issues.

Inclusion of First Nations, Métis, and Inuit health leaders and medical and research experts in national and provincial/territorial decision-making is crucial to addressing inequities that exist in diagnostic, assessment, and treatment services. Targeted funding and inclusive practices are needed to create safe and productive spaces that respect and value input from Indigenous leaders, persons with lived experience, and medical and research experts. Prioritising dialogue and collaboration across Indigenous groups living in the Circumpolar North is also key to better understanding the needs of Indigenous patients and families living in these regions.

In consideration of the above, the following recommendations are provided:

- The establishment across health jurisdictions of culturally safe mechanisms for First Nation, Métis, and Inuit patients and families to differentially self-identify within transplant-related administrative and health utilisation databases. Included in this effort is entrenching the data sovereignty rights of distinct Indigenous groups in relation to data governance and dissemination.
- A review of compliance processes and requirements to identify biases that potentially exclude Indigenous peoples from becoming transplant donors or recipients.
- In partnership with Indigenous health leaders, Knowledge Keepers, Elders, and patient/families with lived experience, ODT programs develop and adopt culturally-appropriate curriculum and anti-racist training that educates ODT teams about the specific challenges and needs of Métis, First Nations and Inuit patients and families across the spectrum of ODT services.

- The development of Indigenous-generated public health education and programming, and the advancement of strategies and interventions that aim to reduce the geographic, financial, human resource and other gaps and barriers facing rural and remote Indigenous peoples needing care for end-stage organ failure, transplantation, and living donation.
- National funding be provided to Indigenous health-care leaders to convene an international Indigenous working group to review established ODT strategies from the perspective of distinct Indigenous groups, including Indigenous peoples living in the Circumpolar North.

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