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### Rights and health versus rights to health: Bringing Indigenous Peoples' legal rights into the spaces of health care services

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## Rights and health versus rights to health: Bringing Indigenous Peoples' legal rights into the spaces of health care services

Sarah E. Nelson, Kathi Wilson

### ABSTRACT

The political-legal discourse of Indigenous rights continues to be separated from discussions of health care services in geographic scholarship, due to the ways in which political-legal, settler-colonial definitions of rights fail to take Indigenous understandings into account, as well as a distrust on the part of scholars of the limited and contingent notion of "rights." While Indigenous rights, inherently tied in Canada to recognition by the settler-colonial state, have limited application in achieving social justice or decolonization for Indigenous peoples, we argue that Indigenous rights can be used as a complementary discourse to Indigenous resurgence, within broader discourses of Indigenous justice, to lend legal and political weight to arguments for cultural safety and human rights in health care. We draw on a study conducted with 50 Indigenous community members and 15 health services professionals in the northern city of Prince George, Canada, to elucidate how Indigenous peoples' experiences in health care settings may be improved by giving attention to rights discourse and removing the geographic and identity-based limitations of Indigenous rights to health care in Canada.

#### Keywords:

Indigenous rights; Indigenous peoples; Health care services; Social determinants of health; Colonialism; Canada

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#### 1. Introduction

Conceived of as fundamentally political, the ways in which rights are brought to bear on studies of health, health care, and medicine are varied and contentious, both in Canada and worldwide. Rights, understood via international declarations such as the United Nations Declaration on Human Rights, or through foundational national documents such as the Canadian Charter of Rights and Freedoms, are used to substantiate calls for social justice but have also been subject to intense academic scrutiny and critique (Alfred, 2009; Borrows, 1998; Simpson, 2011).

In the context of the rights of Indigenous peoples in Canada as in many other settlercolonial states, "rights" as individualized entitlements stem from a liberal, egalitarian mode of thinking with foundations in colonialism, that can serve to obscure discussions of collective rights or Indigenous principles of responsibility (Kulchyski, 2013; Lalibert e, 2015). In this paper, we use the term "settler-colonial state" to refer, in general, to countries that have come into being through the colonization and occupation of Indigenous peoples' land. Because of the ways in which Indigenous rights are tied to recognition by the settler-colonial state, scholars have pointed out that Indigenous rights discourse is inherently limited by colonial state interests, leading to a disconnect between legal rights and rights in practice, and severely limiting the potential for Indigenous rights to address ongoing colonial wrongs (Correia, 2018; Coulthard, 2014; Simpson, 2017).

In spite of the shortcomings of rights as a concept, Indigenous rights have been utilized around the world as a framework for achieving social justice (Correia, 2018; Mazel, 2018). In this paper we seek to spark dialogue about Indigenous rights with respect to health care services. We bring rights discourse into the context of health services because of the fundamentally political nature of health disparities for Indigenous peoples worldwide – that is, the ways in which political structures of colonialism act as determinants of Indigenous peoples' health (de Leeuw, Maurice, Holyk, Greenwood, & Adam, 2012; O'Sullivan, 2012). Engaging with rights discourse is also timely, in order to acknowledge the expanding power of Indigenous rights movements in Canada and beyond, and to explore the possibilities and limitations of the concept when it comes to health and health care.

#### 1.1. Background: existing literature on health and rights

Geographers engaging with rights put forward many important ways of understanding the concept, yet rarely put these into dialogue with scholarship on health and health care. Indigenous rights are generally treated by geographers and policymakers in terms of claims to land and resources (Carmalt, 2018; Correia, 2018), which tie Indigenous rights intimately to concepts of place (Castree, 2004; Coombes, Johnson, & Howitt, 2014; Pearce & Louis, 2008) – yet these concepts of place are not often extended to examinations of health care settings. Some geographers have called for deeper engagement with discourses of human rights – such as rights to dignity and to life – and the responsibilities associated with them when it comes to Indigenous peoples' health and well being (Carmalt, 2018; Lalibert e, 2015) but overall, there has been only limited engagement with rights when it comes to health care services.

Scholarship on access to health care services maintains a focus on individual people's access to services, making collective Indigenous rights seem to exist separately from these particular contexts (Calabrese, 2008; Marrone, 2007; Maxwell, 2014). Instead, we argue – following scholars such as de Leeuw (2016) – that honouring (or failing to

honour) collective Indigenous rights impacts people at an individual scale. Collective rights need to be recognized overtly in the planning and delivery of health care services, if justice and equity for individuals accessing health services are to be achieved. Integrating discussions of Indigenous rights with Indigenous peoples' relationships with health care requires taking understandings of Indigenous rights beyond their association with colonial understandings of territorial boundaries, land title, and natural resources (Daigle, 2016), to encompass concepts of place and health that are intimately tied to land – land that extends to urban areas and encompasses the spaces of health care in Canada.

Literature on Indigenous health and health care in Canada repeatedly confirms that colonial structures and processes operating at a large scale – such as colonialism embedded in government policies and legislation - impact the small-scale, individual, medicalized, and embodied experiences of Indigenous people in health care services (Browne & Varcoe, 2006; Gone, 2013; Kurtz, Nyberg, Van Den Tillaart, Mills, & The Okanagan Urban Aboriginal Health Research Collective, 2008). The death of Atikamekw woman Joyce Echaguan in a Qu ebec hospital while being taunted by health care staff, and games played by staff in at least one BC emergency department guessing the blood alcohol level of patients they presumed to be Indigenous, provide appalling examples of the current problems related to structural racism against Indigenous peoples in health care in Canada (Barrera, 2020; Lowrie & Malone, 2020). Such structural racism stems directly from Canada's settler-colonial history (Allan & Smylie, 2015; Loppie, Reading, & de Leeuw, 2014). In other words, colonialism and its associated denial of Indigenous peoples' inherent and legal rights, has been demonstrated to be a fundamental (social) determinant of health for Indigenous peoples in Canada (Czyzewski, 2011; Greenwood, de Leeuw, Lindsay, & Reading, 2015; Reading & Wien, 2009).

A few geographers and health and legal scholars have drawn connections between the geographies of Indigenous rights and Indigenous peoples' health. This work highlights the tensions between rights as a state-oriented discourse informed by colonialism, and its potential as a tool in fighting to improve Indigenous peoples' health. In the Australian context, O'Sullivan (2012) examines how discourses of human rights expose the ways in which Indigenous health policy is ineffective at closing the gap between Indigenous and non-Indigenous health outcomes – even as human rights discourse becomes embedded in Indigenous health policy at the national level. Mazel (2018) examines how Indigenous communities in Australia use human rights discourse strategically to advocate for better health and socioeconomic outcomes, influencing human rights discourse in the process.

In Canada, scholars have focused on legal rights extended to Indigenous communities as an avenue to improving Indigenous peoples' health. Boyer (2003) draws on Indigenous rights enshrined in the Canadian constitution to argue for a legal right to health. Senese and Wilson (2013) examine urban Indigenous community members' perspectives on how the recognition – or lack thereof – of Indigenous rights impacts their health in Toronto. There are important distinctions, as well as important areas of overlap, between human rights and legal rights when it comes to Indigenous health (Kulchyski, 2013).

Given the ways in which national and international rights frameworks are being deployed as a tool to fight against colonialism, in Canada and beyond – colonialism which, again, is a fundamental determinant of Indigenous peoples' health – a discussion of the ways in which Indigenous rights might change the ways in which health care services respond to the needs of Indigenous peoples is warranted. With the exception of the study by Senese and Wilson (2013), Indigenous community members' access to health care services have yet to be analyzed in the context of Indigenous rights to health in Canada, in the context of legal rights as guaranteed under the Constitution Act. This paper seeks to engage with debates about Indigenous rights discourse in health care services, using the example of one city in Canada. It does so through an examination of qualitative interviews and focus groups with 65 individuals – 50 Indigenous community members and 15 health services workers (both Indigenous and non-Indigenous) – in the city of Prince George, Canada.

#### 1.2. Background: Indigenous rights and health in Canada

Before we proceed to a discussion of Indigenous rights in Canada, it is important to explain the terminology that we use in this paper. According to the Canadian Constitution Act, 1982, "Aboriginal peoples of Canada' includes the [First Nations], Inuit and M´etis peoples of Canada" (Government of Canada, 1982). Where necessary, in this paper we use the legal term "Aboriginal" in relation to rights – but more often we use the collective term "Indigenous," a more generally accepted international term referring to the original peoples of a place. When speaking about rights, it is often necessary to use these collective terms, but we do so with the recognition that Indigenous peoples generally strongly prefer the use of specific names – such as Cree, Mi'kmaq, or Om`amiwinninì.

For the purposes of this paper, Indigenous rights include negotiated rights of selfgovernment as well as inherent rights to self-determination (United Nations Declaration, 2008, p. 10). Our discussion of rights is centred on political-legal concepts of rights articulated by the Canadian state and international bodies, rather than on concepts centred in Indigenous communities, which we recognize to be a limitation. However, existing political-legal rights frameworks are being utilized in many parts of Canada to protect the relationships of Indigenous communities with land, and we believe that these frameworks also have value in the case of health care services. Self-government refers to "the delegation – through negotiation – of administrative authority from the state to Aboriginal/Indigenous institutions" (Walker, 2006, p. 2347). Self-determination is a broader and more comprehensive concept that: Encompasses cultural, economic, political, and legal content and refers to the inherent right of Indigenous peoples to continue governing their own affairs through the reform of relations within the settler state in which they are located. (Walker, 2006, pp. 2346–2347)

In Canada, the Constitution Act states that "the existing Aboriginal and treaty rights of the Aboriginal peoples of Canada are hereby recognized and affirmed" (Government of Canada, 1982). "Aboriginal rights" in this case refer to inherent rights of Indigenous peoples, and treaty rights refer to those outlined in historical or contemporary treaties or land claims (Government of Canada, 1982).

In spite of this recognition, those Indigenous rights acknowledged by the Canadian federal government in practice tend to be restricted to access to services such as education and health services, or limited rights to resource use or to self-government (Government of Canada, 2010; Senese & Wilson, 2013). Rights to services, including health care services and health-related benefits provided by the federal government, are limited to Indigenous individuals who are registered under the Indian Act and who live on a reserve – with the exception of some limited federal support for vision, dental, and medical transportation benefits for First Nations people living off-reserve (called "non-insured health benefits") (Lavoie, Forget, & Browne, 2010). Federally-recognized rights to self-government are limited to those practices and groups that can be proven to be continuous with pre-contact societies, with the courts refusing to engage with Indigenous rights to societal change, contemporary governance, or economics (Borrows, 2002, 2015).

In Canada, reserves are small parcels of land held in trust by the Crown for the use of Indigenous groups. The federal government distinguishes between those Indigenous people eligible for registration under the Indian Act, also referred to as "status" First Nations people, and all other Indigenous peoples who are called "non-status." Only status First Nations, about 45 per cent of the Indigenous population in Canada, are deemed eligible by the government to live on reserves and receive federal services, including health services (Government of Canada, 1985; Laliberte, R.; Settee, P.; Waldram, J.B.; Innes, R.; Macdougall, B.; McBain, L.; Barron, 2000; Lavoie et al., 2010).

Indigenous rights have been enshrined in Canada's Constitution Act for decades, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) is currently being integrated into Canadian legislation at the provincial, territorial, and federal levels. However, the gap between recognition of Indigenous rights, and implementation of measures to uphold those rights, remains wide (Borrows, 1998; Correia, 2018). The Canadian government endorsed UNDRIP in 2011 but has yet to enact legislation to align its laws with the declaration (Hudson, 2020). The province of British Columbia (BC) passed legislation in November of 2019 to bring provincial laws in line with UNDRIP. This recognition of Indigenous rights was, however, seemingly undermined almost at the same time that the province of BC committed to them, in a conflict between the Canadian federal and BC provincial governments and the hereditary chiefs of the Wet'suwet'en, an Indigenous nation whose unceded territory covers a large portion of northern BC. The conflict, which grew into nation-wide protests sparked by the federal government's decision to intervene using force, centred on a natural gas pipeline opposed by Wet'suwet'en hereditary chiefs that provincial leadership endorsed building on unceded Wet'suwet'en territory, with or without the support of the hereditary chiefs. The federal government utterly failed to adhere to UNDRIP principles in addressing this conflict. Provincial leadership, for their part, insisted that BC's UNDRIP legislation had not yet come into effect, providing another example of how, in the context of settler colonialism, Indigenous rights are recognized in policy but not upheld in practice (for more on this conflict and the ways in which it highlights unresolved issues around Indigenous rights in Canada, see Kestler-D'Amours, 2020).

This conflict clearly shows the gap between rights recognition and the implementation of measures to protect such rights – a gap that in turn is a large part of the reason that scholars resist turning to the notion of "rights" when seeking ways to achieve Indigenous justice (Coulthard, 2008; L. B.; Simpson, 2017). The way in which this dispute is resolved in the long term by federal and provincial governments will set the tone for the governments' engagement with UNDRIP legislation in both British Columbia and Canada. The insistence of Indigenous leaders and protesters across Canada on the inherent rights of the Wet'suwet'en hereditary chiefs to make decisions about what happens on their unceded land, will set precedents for how Indigenous rights are understood and recognized going forward.

For the moment, recognized Indigenous rights remain geographically limited – to reserves or to small portions of traditional territories – and generally exclude urban areas, with the exception of the small number of urban reserves in Canada (Peters, 2007). Federal policy related to urban Indigenous peoples' health remains restricted to members of federally-recognized First Nations who are registered under the Indian Act. This is despite calls having been made for decades by scholars, independent commissions, and policy analysts to expand entitlements to rights, services, and benefits for urban Indigenous people and those not affiliated with a reserve (Browne, McDonald, & Elliott, 2009; Cardinal & Adin, 2005; Hanselmann, 2001; Place, 2012; Snyder, Wilson, & Whitford, 2015). The 2016 Supreme Court of Canada decision in Daniels v. Canada required that M etis peoples – the most highly urbanized of the three federally-recognized Indigenous groups – be included under federal government responsibilities for "Indigenous peoples," yet has not to date resulted in action on the part of the federal government in terms of entitlement to benefits and services (MacDougall, 2016).

The Report of the Royal Commission on Aboriginal Peoples (RCAP), published over twenty years ago, employs strong language in 25 recommendations with respect to the need to reorganize health care services in conjunction with legal rights for Indigenous peoples in Canada – importantly, including urban communities along with those in rural or reserve areas. It is worth returning to previous calls to action such as those found in RCAP, as well as attending to court mandates such as in the Daniels decision, in order to create legislation and policy that more thoroughly and responsibly upholds Indigenous inherent and treaty rights in all areas of Canada, including in urban settings. Such attention to rights would have important benefits in terms of improving Indigenous peoples' health.

Similarly to other settler-colonial nations, health outcomes for Indigenous peoples in Canada show gaps when compared with the general Canadian population. The impacts of colonialism include violations of the inherent rights of Indigenous peoples to self-government and self-determination; rights that existed prior to European contact and settlement in North America and have never been extinguished (Borrows, 2015; Coulthard, 2014). They also include interruptions of Indigenous healing practices, destruction of Indigenous peoples' food supplies, disruptions of Indigenous families, and many other colonial practices and policies that have directly impacted Indigenous peoples' health (Boyer, 2003; Lux, 2001). If we consider Indigenous rights to be a means of protecting Indigenous lives, governance, and autonomy, the improvement of Indigenous peoples' health can be clearly connected to honouring Indigenous peoples' rights (Boyer, 2003) – or, to the responsibilities of various parties to protect Indigenous physical and cultural survival (Borrows, 2015).

Indigenous rights, as a concept, exemplifies tensions between local place-making struggles and political movements at a global scale (Castree, 2004), but remains disconnected from the intimate and vulnerable spaces of people's experiences in health care. The aim of this paper is to situate Indigenous rights as understood at broader scales (for example, international agreements on Indigenous rights as they play out in national legislation and policy) within the intimate, micro-scale geographies of health care services, through an examination of how Indigenous community members and health service workers living in Prince George, Canada conceptualize Indigenous rights.

#### 2. Methods

This paper draws on the results of a qualitative research study done in the city of Prince George, British Columbia, Canada, between 2012 and 2016. The methods used were semi-structured interviews and focus groups, undertaken using a community-based research methodology based in the principles of decolonizing research. Decolonizing research is an ever-evolving approach to doing research in response to the problems that have been – and continue to be – raised by Indigenous scholars and communities regarding the ways in which academic research has been conducted in Indigenous communities (McGregor, Restoule, & Johnston, 2018; Smith, 1999). Decolonizing research therefore makes an effort to follow the lead of the community in which research is being conducted, and to do research with (or by) Indigenous peoples that will answer questions that are relevant to the community's interests and needs (Castleden, Morgan, & Lamb, 2012; Haig-Brown, 42008; Tobias, Richmond, & Luginaah, 2014).

In the spirit of decolonizing research, the first author spent time discussing the research project and Indigenous peoples' experiences in health care in Prince George prior to beginning the research. From these discussions, a community advisory group of eight Indigenous leaders, Elders, and health care providers and decision makers based in Prince George was formed, who then offered guidance and advice throughout the research. In addition, ethical approval for the research was given from two Indigenous organizations in Prince George, the Northern Health Authority of British Columbia, and the University of Toronto Research Ethics Board.

Prince George is a city in northern British Columbia, at approximately the same latitude as Edmonton, Alberta. It has a population of just over 86,000 people, of whom just under 15 per cent identified as Indigenous in the 2016 Census (Statistics Canada, 2019). This is a relatively high proportion of people, especially when compared with larger cities in Canada. For example, less than one per cent of the population of Toronto identified as Indigenous in the 2016 census – although some research suggests that the number of Indigenous peoples living in Toronto – and other Canadian cities – may be dramatically underestimated in the Census (Rotondi et al., 2017). The proportion of Indigenous peoples in Canada as a whole was almost 5 per cent in 2016 – again, relying on Census data which may provide an underestimate (Statistics Canada, 2017).

Prince George is located on the unceded territory of the Lheidli T'Enneh First Nation, and serves people who come from at least 54 different First Nations in the region, as well as many M etis communities and many Inuit (Aboriginal Health, 2014). Health care in Prince George consists mainly of a large regional teaching hospital; several private practices; walk-in clinics; and a network of not-for-profit organizations providing health care or health-related services. The latter includes Indigenous-led primary health care clinics and other Indigenous-led organizations providing supplemental health care services such as dental clinics, mental health services, coordination of on-reserve health care services. or Indigenous advocacy within health care services.

Elsewhere in Canada, Indigenous people living off-reserve are not eligible for First Nations-specific health care or benefits provided by the federal government, with the exception of non-insured health benefits. In BC, however, including in the city of Prince George, the federal government's role in providing health care for First Nations people is now the responsibility of the First Nations Health Authority (FNHA) (First Nations Health Authority, 2017). The FNHA is a province-wide health authority formed in 2013 that is unique within Canada. Although the FNHA's primary mandate is to serve First Nations people (that is, not Inuit or M´etis), and those living on-reserve (through the federal government's structure of eligibility which the FNHA inherited), the organization has been working to find ways to attend to the needs of Indigenous people living off-reserve and in urban areas, including Prince George (First Nations Health Authority, 2017). Thus, BC and to a certain extent, Prince George are unique in terms of having a dedicated health authority focused on First Nations health and wellness, and provide

examples of both successes and challenges for other regions of the world when considering best practices for the governance of Indigenous health services.

Participants for this study were recruited through networks or groups known to community advisory group members; via posters and social media; by email and by phone. Participants were sought who currently lived in Prince George, and who used both Indigenous-led and non-Indigenous-led health care services in the city of Prince George, or who worked in any type of health care organization that served Indigenous people. A small number of participants described avoiding health care services of any kind, which contributed important perspectives to the research as well.

In total, 50 Indigenous community members and 15 health services workers (employed in Indigenous or non-Indigenous health care services but focused on providing care for Indigenous community members), participated in the study. Twenty-nine one-on-one, semi-structured interviews (21 with community members and 8 with health services workers) and four "group interviews," or focus groups (three with community members and one with health services workers), were held between October 2015 and January 2016. Community members who were interviewed were mainly in the 25–45 age range; 9 participants had been living in Prince George for ten or more years. 42 women and 23 men in total participated in the research. Eight health care providers identified as Indigenous or as having some Indigenous ancestry; 11 worked for Indigenous-focused health organizations and 3 worked in government-run health care institutions. One was an Elder working as a traditional healer and teacher outside of any organization. Interview and focus group questions asked about the ways in which Indigenous community members' rights were perceived as being supported or respected within different types of health care services in the city. What follows is an examination of participants' – both community members and health services workers – responses to these questions.

#### 3. Results

Participants' discussions of rights in health care were grouped thematically into three main categories: violations of rights in health care settings; strategies for supporting peoples' rights; and inconsistencies regarding entitlement to rights. Violations of perceived rights in health care, including rights to dignity, equal treatment, and the right to help when it is needed, were emphasized by both Indigenous community members and health services workers. Movements towards cultural safety, and advocacy on the part of Indigenous-led health organizations, were described as improving recognition of Indigenous peoples' rights in health care in Prince George. Participants also pointed to the ways in which the federal government has created complex geography- and identity-based restrictions of Indigenous rights, especially in an urban setting. In the following sections, interview participants are quoted anonymously according to their role as either "community members" (e.g., "CM 5") or "health services workers" (e.g., "FG 3").

#### 3.1. Violations of the right to receive care

When asked whether Indigenous community members' rights were supported by health care organizations in the city, twenty-six participants - both Indigenous community members and health services workers – described instances in which community members' rights had been violated or disregarded. This was mainly described as the violation of a right to receive care, including feeling that the right to receive care was upheld in some places but disregarded in others; that health care was not provided unless community members or their advocates insisted on it; or that participants were not being given equal treatment compared with other (non-Indigenous) community members. The right to be cared for - more accurately, the principle that when one asks for help, help should be given, was described by one community advisory group member as a culturally-associated sense of what respect and responsibility towards other human beings should involve. In other words, many Indigenous community members from the area might reasonably expect that if they asked for help, it should be given as part of the responsibility of the person who hears the request. Participants described being treated differently depending on where they were accessing services, and feeling that this right to be cared for, or the ability to expect help when it is asked for, was not always upheld. Rights were generally described as being respected in Indigenous-led organizations. As one participant responded, when asked whether they felt that their rights were supported in health care:

Mm, not really. No. Maybe here, when I come to [this Indigenous organization]. That's why I come here a lot, because I feel like I got support here ... They seem to want to help me, so that's where I've been going to get a lot of counseling, is here, too. Like for my health and stuff ... So yeah, I try to come here as much as I can. (CM 11)

This participant described their rights as being upheld when services were offered willingly ("they seem to want to help me"), but stated that this was not their experience in most health care settings in the city.

Violations of the right to receive care were often described using the language of human rights. As one participant put it: Human rights? No, there are some places that, I think they violate your rights, but I just stay away from them, so, doesn't matter to me. (CM 6)

This participant expressed a sense of having had their human rights violated in some health care settings, but articulated a sense of independence as a way of protecting themselves from such violations.

Several participants described having to insist on being cared for before health care would be provided, for example having to seek out a health care provider and specifically ask for something before anyone would come to help. One participant in a focus group discussion described a situation in which their mother was not receiving what they felt was appropriate care, and the subsequent need to be forceful in getting their needs addressed:

When we went to the hospital, when [my mom's] appendix burst, when all of that stuff happened, she was, in the fricking Emergency [department], like, in the hallway, on her bed .... And my little niece ... if she didn't phone me, and it was just her down there, like she wouldn't have been able to be like, 'hey you,' like get, like you know, be pushy like that. (FG 2)

The implication here is that if this participant's niece had not called someone else for support, their mother's health might have been severely compromised through not receiving the care that she required.

The need to speak up in order to receive proper health care was also linked to a sense of being treated differently than other community members would be, because of being Indigenous. As one participant put it: I just know it's a big thing here, it's almost like part of our mandate .... the dignity, the respect .... I won't say that all health organizations do that. I know quite a lot of them don't. Aboriginal rights, whether that's human rights, or if it's the legal rights. So many people are treated so badly, because they're Aboriginal, and a lot of that comes from the government organizations. I have a lot of people come in here and they're like, 'I'm not going back there.' Like, 'they treat me like dirt. They treat me like I'm an Aboriginal person who has no rights. I'm nothing, I'm second rate human.' I've heard lots of people say stuff like that. (HSW 6)

Overall, when asked about whether their rights were upheld in the city, participants frequently described the violation of a right to receive health care on an equal basis with all other people. In some health care settings, participants felt that their rights as human beings were violated. Participants described feeling that they could not expect consistent treatment from different institutions; many described avoiding certain health care spaces altogether; and others stated that they had to play an active role in advocating for themselves or their family members in order to receive the appropriate level of health care for their needs. The reasons participants described for being treated differently were often based on Indigenous identity, and participants described being much more comfortable in health care settings in which help was offered willingly when asked for, in an understanding and non-judgmental way.

#### 3.2. Ways of supporting Indigenous Peoples' rights in health care

Twenty-two participants described ways in which Indigenous community members' rights were supported in health care. Expressed by both Indigenous community members and health services workers, support for Indigenous community members' rights in health care was generally described as changes being made within non-Indigenous health care services to improve cultural safety and feelings of inclusivity and support; or as advocacy work done by Indigenous health organizations and their staff.

Changes being made to non-Indigenous health care services to better accommodate Indigenous peoples' rights were often expressed in terms of cultural sensitivity or cultural safety. For example, one health care worker, who works in a non-Indigenousled health care service, described making accommodations at an organizational policy level as well as at an individual level, as a part of upholding rights:

One way [of upholding rights for Indigenous people], as we mentioned, was to make sure that our policies, for example in smudging, are used to make sure that we're using culturally sensitive spiritual health care. And that becomes very complex for the Indigenous people, because, for example, in this area, often Indigenous people are Roman Catholic, and so there is both, sometimes, a fear of and a desire for end of life ritual in the Roman Catholic tradition. So to be sensitive to that ... and to find ways to work with families that might be in conflict, in and around that. (HSW 4)

This participant described upholding Indigenous people's rights through ensuring that health care is culturally safe, including accommodating specific cultural or spiritual practices.

One community member described cultural safety in terms of taking into account local Indigenous histories in a non-judgmental way: That [Indigenous-led health organization]'s a really nice place too. Like, they don't judge you or anything .... I find that they're way more nicer, yeah [than non-Indigenous health care organizations]. And because I think of the history of, of Natives and stuff like that. (CM 5)

Another health services worker from a non-Indigenous health care organization, whose interview was not recorded, pointed out that when people talk about Indigenous rights they are usually referring to rights to land, resources, or self-government. These rights were felt to be in a separate category from health care. Within health care, this participant felt that what could be done was to improve respect for Indigenous healing traditions and Indigenous perspectives on health care, including, for example, the need to have extended families gather together when someone is sick (HSW 1).

Several health care providers from Indigenous-led health organizations described advocacy as a way of upholding people's rights. For example, one health services worker said:

What I do is if somebody wants assistance going to a doctor's appointment, I go with them, or if I have a client in the hospital, I go to the hospital and I attend family meetings in the hospital, so I make sure the client's needs are being met. And sometimes the client can't get their needs across, and they feel they're not being heard, so then that's what I do. I go to make sure they're being heard and their needs are being met. (HSW 5)

Advocacy was described as an essential part of supporting Indigenous community members' health. In all, when articulating how Indigenous peoples' rights were supported in health care spaces, participants described both the importance of cultural safety and sensitivity within non-Indigenous health care services, and the need to advocate for community members.

# 3.3. Inconsistent geographies and identities with respect to Indigenous legal rights

Eighteen participants – both Indigenous community members and health service workers – spoke about the inconsistent nature of Indigenous rights when it comes to health and health care. Rights were described as being limited based on both a person's identity and geography. Community members and health services workers described differences between support received in the city and on reserve; the inconsistency of status cards or other forms of identification in terms of linking to rights and benefits; and that it can be hard to discern what rights an individual is entitled to because of the complex and inconsistent ways in which Indigenous legal rights are allocated by geography and identity.

When living in an urban setting, participants felt that they did not have access to the same type of financial support for access to health care services, prescriptions, benefits, and travel, as they would have on a reserve. For example, as an Indigenous community member said during a focus group:

Our band around here, they arrange everything. All you have to do is be there. Know what I'm saying? Like, you guys [other participants in the focus group] have to pay for your trip and stuff like that, eh? They should make it all the same .... Even [one Indigenous organization] ... if they don't work with you [i.e. if you are not affiliated as part of a member nation] ... they don't help, right. They sort of bar you off, bar you out, sort of thing, eh. Like if you were ... joined [as] their member, then they do everything for you. (FG 1)

Participants also expressed rights as entitlement to services and financial support, which they saw as being inconsistent depending on where a person lived (geography) or which band they were a member of (identity).

Some participants mentioned status cards or other identification cards when asked about rights. Status cards refer to cards issued by the federal government that are used to identify First Nations people who are registered under the Indian Act – approximately 45 per cent of Indigenous people in Canada (Statistics Canada, 2017). These and other identification cards were described by participants as prerequisites for access to certain rights, whether the right to health care or to other health-related benefits provided by the federal government. Participants described these types of cards as not being extremely useful. One community member, for example, felt that having an identification card was not of much use to them; as they said, "I got a card that says that I'm Métis,<sup>1</sup> and my picture, but it doesn't stand for anything" (CM 5). Several participants expressed this kind of skepticism towards formal Indigenous rights,

1 This card is a membership card for the Métis Nation of British Columbia, which comes with certain rights and benefits but is not recognized by the federal government the way a status card would be.

feeling that there were many barriers in the way of getting identification or status cards as well as that the cards did not bring with them the rights or benefits, such as coverage for prescription medication, that had been promised.

One participant described being happy with the benefits associated with the status card. They responded to a question about rights in the following way: I'm doing good, because in a couple of weeks or maybe this week, [or] next week I'm going to get my status card, so that'll help me .... my rights as a Native person in this community, I think my – I'm not like everybody else out there, like I got, I think I got it made pretty good .... I'm on the right meds ... I got, like, two doctors, so. (CM 10)

This community member associated having a status card with having benefits in terms of Indigenous rights, and considered themselves luckier than many in the urban Indigenous community in terms of their access to health care and medication, and their living situation. This, again, highlights the differential access to rights, services, and benefits that participants perceived among Indigenous community members in Prince George.

The importance of formal or distinct Indigenous rights – including those invoked through status cards, as discussed above – was emphasized by some participants while others distanced themselves from the concept. One non-Indigenous health services worker said, "I do think that there's a specialness to Aboriginal peoples' rights, we need to pay special attention because the general population has made a point not to" (HSW 1). Another Indigenous health services worker, however, felt that most members of their community did not feel a sense of entitlement with respect to Indigenous rights: I would never say, you know, 'it's my right as a First Nations person to get this or that.' Like, it's my right to be treated like a person. But I don't think we really have that, like in my community – I can only speak for my community – I don't think anybody says 'it's our right to this or that.' (HSW 5)

This participant linked Indigenous rights to a sense of entitlement that they did not identify with, instead emphasizing the need for human rights and equal treatment in health care. Although it is important not to generalize broadly based on the opinions of these two participants, it may be important to attend to the differences in how people perceive Indigenous rights discourse, depending on whether or not a person identifies as part of an Indigenous community. This distancing from rights as a sense of entitlement to specific benefits was echoed by one Indigenous community advisory group member who said that having "rights" is not what Indigenous community members are necessarily looking for.

Finally, participants described a need for more information about Indigenous peoples' rights. Participants felt that many Indigenous people in the city, often including themselves, did not know what they were entitled to in terms of Indigenous legal rights with respect to health care, because of the ever-changing nature of rights as defined by the federal government. For example, as one community member said:

R: Is there anything else you want to add?

P: I think more understanding of our rights. Like I don't know – they said that the First Nations health [referring to federal government (now First Nations Health Authority) health benefits offered to First Nations people] always changes, on what we're covered and what's not covered. I don't know. I don't know any of that. (CM 18)

Participants described Indigenous rights as being changeable and inconsistent. In general, participants felt that more information should be provided to members of urban Indigenous communities about their rights, especially when it came to health care. Overall, participants described Indigenous rights with respect to health care as being inconsistent and limited. How people felt that their rights were being respected was often expressed in terms of the inconsistent application of rights depending on where people lived or on how they were identified by the government. Legal rights were also expressed as a set of benefits or services; participants did not see rights to land, resources, or self-government as being applied in the realm of health care.

#### 4. Discussion and conclusions

As noted earlier in the paper and in participants' comments, the discourse of Indigenous rights has limited application with respect to health care services for Indigenous people because of the restricted ways in which Indigenous legal rights have been incorporated into health care policy, for example by limiting who has access to health care entitlements based on on-reserve/off-reserve geographies as well as federally- created identities under the Indian Act. As indicated by participants' responses in this study, Indigenous rights in health care services are perceived to be associated with a right to receive care when needed, a right to culturally appropriate or culturally safe services, or respect for human rights - and were often described as having been violated. There was a strong sense of inconsistency in how and where rights were applied and to whom, leading participants to question what Indigenous rights mean in an urban context, or to distance themselves from the concept. When Indigenous rights become narrowed to a set of benefits or services that are only available in certain places and for people who are identified as Indigenous in particular legal ways defined by the federal government rather than by Indigenous communities, discussions of the inherent rights of Indigenous peoples to self-government and self-determination become essentially absent or consciously separated from Indigenous peoples' rights within health care settings. This separation of Indigenous rights from health care is problematic because it is one mechanism by which large-scale injustices, such as colonial practices and policies, come to appear irrelevant to the more intimate, small-scale practice or provision of health care - when in fact these broader-scale injustices have been repeatedly shown to lead to individual-level, intimate experiences of racism and discrimination on the basis of Indigenous identity.

The three key findings in this paper – participants' experiences of rights being violated; strategies used by health care organizations to uphold Indigenous peoples' rights; and the complexities surrounding entitlement to rights in health care - speak to the impacts of large-scale (for example, national-level) colonial processes on individual people's experiences. First, when asked about rights, several participants responded by sharing experiences of the violation of their right to receive needed services when accessing health care services in the city. Participants felt that this right to receive services when they were needed was honoured in some settings - generally Indigenous-led health care settings - but violated in others; told stories of having to insist on being cared for before care was provided; or reported feeling that Indigenous community members were given poorer or lesser treatment than other community members would receive in health care settings. This finding indicates that the recommendations of the Royal Commission on Aboriginal peoples have still not been addressed; there is an urgent need for Indigenous community members to have better experiences in health care, including better respect for human rights. This finding also points toward perceived discrimination and structurally embedded racism as core problems that participants associate with rights. If participants in this study can repeatedly say that they are asking for help, in health care settings, and their requests for help are being denied, then we have an extraordinarily dangerous situation in which the well-being - the lives - of Indigenous people are being put at risk by the very systems that are supposedly there to protect them. This has been evidenced only weeks prior to writing, in the death of Joyce Echaguan, an Atikamekw women from a community north of Montreal, Quebec, whose cries for help were met by taunts from nurses in a hospital in Joliette, Qu'ebec; and in cruel games played by health care staff that diminished and stereotyped the needs and situations of Indigenous people seeking health care on Vancouver Island, British Columbia (Barrera, 2020; Lowrie & Malone, 2020). These devastating examples of racism and discrimination took place in health care settings whose purpose is ostensibly to protect people's lives and wellness. Such actions (or inactions) are the result of systemic racism and discrimination rooted in the kinds of behaviours that colonial structures allow.

With respect to the second key finding, several participants described ways in which rights were upheld in health care services. These participants acknowledged the difficulties that Indigenous community members often face in health care, but also highlighted the ways in which health care organizations are implementing changes in order to better respect the rights of Indigenous community members. These participants pointed out the importance of both cultural safety and advocacy for Indigenous community members. Attention to cultural safety and advocating for Indigenous peoples' needs, in health care and beyond, were perceived as counteracting the racism that Indigenous community members often experience in health care settings – racism that is linked, in participants' responses as well as in the literature, to large-scale colonial processes of dispossession of Indigenous land and rights. Cultural safety is an important teaching tool and strategy for achieving equity in health care services, for Indigenous people and other racialized groups (Browne et al., 2016). Teaching cultural

safety in the context of Indigenous rights could add legal justification to the moral and ethical rationale for implementing cultural safety in health care, and help to further contextualize the provision of health services in light of broader injustices such as colonial dispossession.

Finally, participants reported differences in access to rights, in terms of financial support, health services, and benefits, between urban areas and reserves, and also depending on what group, band, community, tribal council or First Nation a person was a member of. Participants emphasized the fact that 'Indigenous people' are far from one homogenous group, and that Indigenous peoples have dramatically different access to rights depending on differing geographies and legal identities. These distinctions highlight the political complexities of Indigenous legal rights, as successive federal governments in Canada have created careful delineations between groups of Indigenous peoples living in differently classified spaces, in the process defining different Indigenous identities and associating only some of these identities with entitlement to limited government rights and benefits. This political-legal complexity obscures Indigenous rights to self-definition and self-determination, and limits recognition of Indigenous connections to land and healing practices associated with healthy relationships to land and place.

There is extremely limited recognition of Indigenous legal rights on the part of the federal government, when it comes to health care. As Senese and Wilson (2013) explain:

Though generally construed as the inherent, collective rights of Aboriginal peoples, what Aboriginal rights have meant practically has been a set of services and benefits ... that are provided by the federal government for status First Nations who live on reserve (apart from post-secondary education assistance and Non-Insured Health Benefits (NIHB), which are available off-reserve). (p. 221)

Participants in this study described the effects of these limitations in their experiences of accessing health care and associated health care benefits. Colonialism as a determinant of Indigenous peoples' health is a recurrent theme in Indigenous health literature, both in Canada (Greenwood et al., 2015) and beyond (O'Sullivan, 2012). Experiences of racism, including in health care, are part of the mechanism through which colonialism impacts Indigenous peoples' health (Allan & Smylie, 2015; Loppie et al., 2014). The structural racism that becomes embedded in the health care system and is expressed in individual behaviours (Browne, 2017) is one and the same with the structural racism underpinning the limitations and boundaries placed on Indigenous legal rights over land and natural resources, and restrictions on Indigenous communities' rights to self-government. All of this has its foundation in the ongoing colonial desire for control of Indigenous peoples' land (Blackburn, 2007; Borrows, 2015).

Participants' descriptions of violations of the right to receive care, specifically the feeling that some health care organizations are reluctant to provide them with health care, has a dark kind of resonance with Borrows' (2002) observations that Indigenous rights as articulated by the Canadian settler-colonial state (among others) do not seem to have as their goal the actual physical survival of Indigenous peoples. Participants described situations in which Indigenous community members have to speak out, often forcefully, in order to receive a basic level of health care - something that is in policy guaranteed as a fundamental right to all Canadians, even if it is inconsistently achieved in practice (Harrington, Wilson, Rosenberg, & Bell, 2013; Health Canada, 2017). Sadly, these results are not unique to this study but have been reported many times in different contexts in Canada (Allan & Smylie, 2015; Browne, 2017; Evans, White, & Berg, 2014; Hole et al., 2015; Kurtz et al., 2008). The stated aims of a universal health care system to ensure health for all peoples cannot be achieved when rights to those activities and services that provide for the physical survival of Indigenous peoples are not fully upheld and forthcoming. In this respect, calls for greater attention to human rights, and the responsibilities of all levels of government, health care decision makers, and the general public to protect Indigenous lives, cultures, and freedoms, must be heeded. Health care that is perceived to violate Indigenous people's basic human rights on an ongoing basis is in desperate need of change, and discourses of universal human rights can be used to draw attention to both moral and legal requirements for change.

Problems with the concept and the application of Indigenous rights, as being overly dependent on recognition by the colonial state, have led scholars to propose alternative decolonial strategies, championing resurgence and restitution over rights and reconciliation (Alfred & Corntassel, 2011; Coulthard, 2008; L. B.; Simpson, 2017). The importance and impact of strategies and movements towards Indigenous resurgence in Canada cannot be overstated. These strategies and movements include the actions on the part of, and in support of, the Wet'suwet'en hereditary chiefs; national-level strategies to raise awareness such as the Idle No More movement; and the commitment to exposing and rectifying the ongoing problem of missing and murdered Indigenous women, girls, and two-spirit people (Morton, 2016). They also include smaller-scale, grassroots movements to revitalize Indigenous languages or retain protection for wild rice beds, for example, that take place at the individual or community level. Participants in this study, and Cree, Dakelh and Algonguin Elders from whom the first author has been learning over the course of the past decade or more, prioritize responsibility over the sense of entitlement inherent in having rights. It is therefore perhaps more relevant to think about expectations - such as the expectation of receiving help when it is needed – and the responsibilities of all parties involved in a health care interaction. Because the overwhelming focus of interviews and group discussions in the present study was on legal rights or human rights to health care, we do not feel that we can do justice in this paper to the ways in which Indigenous conceptions of rights and responsibilities link to health care. This represents an important area for future research. This paper's focus on the discourse of political-legal and human rights, however, should not be interpreted as a dismissal of concepts of responsibility, nor as a rejection of

resurgence movements or scholarship. Instead, rights can be seen as a tool for injecting concrete awareness of the effects of Indigenous dispossession into the policy and practices of health care in Canada, that can operate alongside resurgence movements and highlight important areas of responsibility for all parties involved in designing and providing health care.

These findings can draw usefully from work in the geographies of Indigenous rights. Blomley (1994) and other geographers emphasize not only the spatiality of rights, but that the utility of rights discourse may be dramatically different depending on the space in which it is deployed (James, 2013; Purcell, 2013). Blomley points to the difference, for example, between claiming rights in community settings and claiming rights in court (1994). Participants' distinctions between individual rights to dignity and respect, and the legal rights and benefits accessed through the government, reflect such a placebased distinction and highlight perceived differences between the spaces of health care and the spaces of Indigenous legal rights – differences which, we argue, are counterproductive in the pursuit of equitable health care and social justice for Indigenous peoples.

The geographies of rights research also emphasizes the "scaling up" that happens in rights discourse when local violations of, or agitations for, human rights are linked with global human rights and Indigenous rights movements (Lalibert e, 2015; Mazel, 2018). Supporting the human rights of Indigenous community members and the right to receive care at an extremely local, individual scale, when combined with advocacy in the broader community, can have impacts at broader scales. What is needed to close gaps in health outcomes and access to health care between Indigenous and non-Indigenous individuals and communities is action at this local scale combined with the achievement of self-government and self-determination. As many scholars have pointed out, action to improve Indigenous peoples' health and bolster self-determination needs to be taken at multiple scales simultaneously. (Greenwood et al., 2015; Loppie Reading & Wien, 2009; Tuck & Yang, 2012).

The Report of the Royal Commission on Aboriginal Peoples (RCAP), published in 1996, strongly advocates upholding legal rights for Indigenous peoples in Canada – whether in urban, rural, or reserve areas – in the planning and implementation of health care. The RCAP report explicitly recognizes the fundamental need for self-government in health for Indigenous peoples. The report recommends that: Governments recognize that the health of a people is a matter of vital concern to its life, welfare, identity and culture and is therefore a core area for the exercise of self-government by Aboriginal nations. (Royal Commission on Aboriginal Peoples, 1996, s.3.3.2)

The Truth and Reconciliation Commission of Canada (TRC)'s more recent Calls to Action include six recommendations dealing with health and health care. Among them is a call for the recognition of legal and treaty rights to health care, although these rights are no longer explicitly described using the language of self-government: We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties. (Truth & Reconciliation Commission of Canada, 2015, call to action no. 18)

This recommendation refers the reader to legislation and treaties that advocate for selfgovernment, but without explicitly making links between self-government and health in the text of the recommendation itself.

In spite of the continued need for action with respect to health care in Canada for urban Indigenous peoples as well as attention to rights in the context of health care, the TRC's calls to action fall short when compared with the RCAP recommendations, in terms of the number of recommendations, the language used, and the extent of recognition of Indigenous rights, especially in urban areas. Although they have been much more widely acknowledged in public discourse by the federal government, Canadian media and other institutions than RCAP was, the TRC's calls to action have been criticized for focusing on individual-level reconciliation rather than large-scale, institutional, and national-level change; and for sidestepping or de-emphasizing Indigenous rights to selfgovernment and self-determination in favour of discourses of healing and forgiveness (De Haas, 2017; Jewell & Mosby, 2019). The results of this study as well as the work of many scholars indicate that healing from the impacts of residential schools and other colonial policies and actions takes more than attention to individual medical or healthrelated needs; it requires attention to ongoing colonial structures and processes including health care systems – as well as action to make fundamental change. Indigenous rights to self-government and self-determination need to be acknowledged within health care services as processes that fundamentally impact Indigenous peoples' health, as part of taking steps to make health care services more responsive to Indigenous peoples' needs.

Moving forward, studies of Indigenous health should explicitly take into account Indigenous legal rights, responsibilities of all levels of government, and Indigenous perspectives on health, rights, and responsibilities when investigating the provision of health care for Indigenous peoples in Canada. This would highlight the responsibilities of various actors in health care settings to uphold both human and Indigenous rights (Lalibert e, 2015), expanding geographical scholarship on rights and holding various levels of government to account. Future research should also take on the task of investigating how to develop alternative mechanisms by which Indigenous legal rights and human rights can be asserted and protected in health care in urban areas.

The findings of this study show that health care leaders, practitioners, and policy makers need to remember the recommendations of the Royal Commission on Aboriginal Peoples from so many years ago, in order to draw attention to what has still not been accomplished with respect to urban Indigenous health and Indigenous rights to

health care and self-government in Canada. Structural racism must be rooted out. No more people should die due to negligence or be denied appropriate and timely health care within the Canadian health care system. The foundational impact of colonial policy and structures on Indigenous peoples' health is recognized by the TRC, as is the need to revisit health care funding and policy structures. Action in these areas should be complemented by attention to Indigenous legal and inherent rights to self-government and self-determination, in the pursuit of health equity for Indigenous peoples in Canada.

#### **Declarations of interest**

None.

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