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Résumé de l'article

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Accessing Indigenous Long-Term Care

Danielle Gionnas[a], Andria Bianchi[a,c,d], Leonard Benoit[b], Kevin Rodrigues[a,c]

Résumé
L'objectif de ce commentaire est de présenter et de combler les lacunes existant dans l'offre de soins de longue durée en établissement culturellement inclusifs pour les peuples autochtones de l'Ontario. Après avoir présenté des statistiques sur la population autochtone et les options de soins de longue durée, nous soutenons que nous avons la responsabilité éthique d'offrir des options de soins de longue plus inclusifs sur le plan culturel.

Mots-clés
Autochtones, soins de longue durée, équité, inclusion culturelle

Abstract
The purpose of this commentary is to present and respond to the gap that currently exists in providing culturally inclusive residential long-term care options for Indigenous peoples in Ontario. After presenting statistics regarding the Indigenous population and long-term care options, we argue that we have an ethical responsibility to offer more culturally inclusive long-term care.

Keywords
Indigenous, long-term care, equity, cultural inclusivity

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CASE

Mr. X is an 85-year-old male who originally presented to the emergency department via ambulance due to chest pain. He underwent a cardiac catheterization and was diagnosed with ischemic heart disease. Given the significance of the disease, a coronary artery bypass grafting (CABG) was proposed to improve blood flow to his heart. Mr. X consented to the surgery, which went successfully. A few days later, Mr. X developed a hospital acquired infection. As a result, he lost the ability to walk and spent most of his days sleeping. Once his infection cleared and he had recovered from surgery, the clinical team felt that it would be in Mr. X's best interest to go to a rehabilitation unit to make further functional gains. Mr. X previously lived independently and wanted to return to his home, which is located in a five-story apartment building that only has stairs.

Mr. X was transferred to a geriatric rehabilitation unit. After working for two weeks to make functional gains, the clinical team informed Mr. X that he might be unable to return home. He was classified as a high falls risk patient, required a wheelchair, and was unable to successfully complete activities of daily living. The team proposed discharging him to a long-term care facility. Mr. X was amenable to the proposal, but expressed that he would not be willing to go to a long-term care facility where he would be primarily cared for by non-Indigenous staff. At this time, Mr. X informed the care team that he was an Indigenous person who was a residential school survivor. He experienced significant abuse as a child and now lived in an Indigenous community, to which he remained connected. While he was open to receiving care from a Western healthcare institution for a temporary period of time, he was not willing to call a non-Indigenous living environment "home"; any such place would evoke strong memories of his residential school experience where his Indigenous traditions and language were unwillingly removed from his life, leading to the enforcement of Western values and subsequent trauma from these actions.

INTRODUCTION

Mr. X's case provides a glimpse into a gap that exists within Ontario's long-term care system. While similar issues may exist in other Canadian provinces and the conclusions of this article may be more broadly relevant, given the authors' professional experiences, the content of this paper will focus on Ontario.

The rise of an aging population calls for an increase in suitable long-term care services. Yet, many citizens still encounter long wait times and inadequate services (1-25). Additionally, what is often overlooked when it comes to considering long-term care is whether we are responding effectively, or at all, to the needs of Indigenous peoples. This may involve caring for their physical, spiritual, emotional, and mental well-being by providing holistic practices and connections to family, community and land (26). The inability and/or unwillingness of the federal and provincial governments to take responsibility for providing long-term care to Indigenous populations has produced an absence in care provision (27). Moreover, despite Canada's reputation as a diverse and inclusive nation, many aspects of society do not demonstrate cultural inclusivity. In the case of Indigenous peoples, the absence of cultural inclusivity has been a longstanding issue. For instance, our healthcare system was developed on a foundation of systemic racism, which continues to facilitate and force assimilation into "mainstream" healthcare treatment and disregard Indigenous practices and perspectives (28). Acknowledging Canada's discriminatory and oppressive history toward

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Indigenous peoples resulted in the creation of the Truth and Reconciliation Commission (TRC), which was an attempt to acknowledge and reconcile the oppressed history experienced by Indigenous peoples through calls to action, as well as to establish relationships based on mutual recognition and respect (29). The TRC was a positive step forward in recognizing and responding to injustices that Indigenous peoples face in Canada; one of the goals was to provide culturally safe care, as well as space for communities, families and former residential school students to share their experiences (29). Culturally safe care promotes healthcare provision that is based on respectful engagement across differing cultures and efforts to address power imbalances in the healthcare system (30).

There is still a long way to go in remedying Canada's relationship with Indigenous peoples. This is made clear through examples such as the Indigenous experience in Ontario's long-term care sector. Despite some availability of culturally inclusive long-term care programs, most Indigenous patients remain in non-Indigenous outpatient assisted living programs, leaving a gap in live-in long-term care; the existence and potential reasons for this gap will be explored below. In light of the current context, we argue that Ontarians have an ethical responsibility to increase access to culturally inclusive live-in long-term care facilities for Indigenous peoples. This paper will defend an argument for such a responsibility. We first present the current statistics of Indigenous peoples living in Ontario and then reflect upon the province's long-term care system; subsequently, we describe what constitutes culturally inclusive long-term care, and discuss how it fares in offering the type of care that may be relevant to some Indigenous peoples. Finally, we discuss the ethical significance of providing culturally inclusive long-term care for Indigenous peoples, and layout next steps for consideration.

NUMBERS IN ONTARIO

In Canada, 1,673,780 people – 4.9% of the nation's population – identify as Indigenous (31). In the province of Ontario, there were 374,995 individuals who identified as Indigenous in the 2016 census, making up 2.8% of the provincial population (32). Within Ontario, many of the larger cities have Indigenous populations exceeding 10,000 people. These cities include Toronto, Ottawa-Gatineau, Sudbury, Thunder Bay, Hamilton, London, and St Catharine's-Niagara (33). There are also smaller cities in Ontario with populations that include a higher proportion of Indigenous peoples; this was indicated in the census based on whether the city's total population was comprised of 10% or more of Indigenous peoples. These cities are almost exclusively in Northern Ontario, including Kenora, Midland, Thunder Bay, Sault St. Marie, Timmins, Pembroke, Sudbury, North Bay and Elliot Lake (33). It is also critical to note that these statistics only account for Indigenous individuals who partook in the Canadian census, and does not include those who declined to participate or did not identify as Indigenous.

In addition to recognizing the total number of identified Indigenous peoples, it is also important to include the age of the population when considering who may require access to long-term care, since 93.4% of long-term care residents are over the age of 65 (34). The average age of Ontario's population is 41 years old and 16.2% of the population is aged 65 and over (32). In terms of the Indigenous population, the average age in Ontario is 33.6 years of age while only 7.3% of this population is 65 and over (32). With regards to the statistical differences that exist between the age of Indigenous and non-Indigenous peoples in Ontario, it is thought that a poorer state of overall health stemming from the transgenerational trauma of colonialism, as well as discriminatory policies and gaps in federal healthcare programming for eligible Indigenous individuals, plays a significant role in the lower life expectancy and average age of Indigenous peoples (27).

LONG-TERM CARE IN ONTARIO

In the province of Ontario, there is an increasingly high demand for long-term care. The provincial government's provision of long-term care provides residents with constant access to medical care and assistance with daily activities in a safe, home-like environment (34). Long-term care facilities are starting to provide more person-centred care, which involves considering each resident's lifestyle, habits, preferences, and practices when developing their care plan (35). It is worth noting, however, that at the time of writing this commentary, some aspects of a person-centred approach, such as family contact and spiritual needs, have been adversely affected by the COVID-19 pandemic (35,36).

Long-term care services are available through a network of live-in long-term care homes and assisted living programs throughout the province. Eligibility for care is determined through criteria outlined in provincial regulations, which all long-term care facilities are mandated to follow (34). As of May 2019, there were more than 94,000 Ontarians on waitlists for a room in a live-in long-term care facility (1-24). The waitlists for each long-term care home vary drastically. The reason for this variation is that individuals typically apply to long-term care facilities based on proximity to their friends and family, the activities they value, as well as the moral and cultural values of the homes, with the result that certain homes have longer waitlists than others (1-24).

Although the availability of long-term care options for all Ontarians is staggeringly low, it is likely that Indigenous peoples in Ontario experience additional challenges when it comes to finding culturally safe options for live-in settings. While there are some culturally inclusive long-term care programs available, these programs are more densely located in cities and regions with higher Indigenous populations (37-42). The location of these programs makes it such that people from other regions must choose to either move away from their friends, family, and community in order to receive culturally safe care, or live close to their friends, family, and community but receive care that may not be sensitive to the needs and values of Indigenous peoples. Additionally, the vast majority of these programs are day programs, allowing citizens to remain in their home environments, perform daily activities (e.g., managing medication and maintaining personal hygiene), and receive any required medical care

and attention (43). The day programs assist people who have a certain level of functional and cognitive independence such that they do not require extensive care, and they take into account the cultural values and activities that may be important for Indigenous peoples (e.g., to maintain a close and connected relationship with their community and environment) (32).

Once an individual can no longer safely age in their home community, then the availability of a bed in a live-in long-term care facility often becomes vital (43). Two types of long-term care options exist in Ontario for Indigenous peoples: 1) Indigenous long-term care homes, which provide culturally inclusive care to primarily Indigenous residents and 2) long-term care homes that provide care to residents from various cultural backgrounds (44). However, culturally inclusive live-in long-term care options for Indigenous peoples (i.e., option 1) are incredibly rare. In Ontario, there are only two known live-in long-term care facilities for Indigenous peoples: Iroquois Lodge in Ohsweken (45) and Meno Ya Win Health Centre in Sioux Lookout (46). Due to the deficit of available options that respond to their specific needs and values, Indigenous peoples are often forced to join waitlists for Western health directed live-in long-term care facilities if they want to receive necessary care in a timely manner and remain in close proximity to their home community.

The biggest differences between culturally inclusive long-term care homes for Indigenous peoples and Western long-term care facilities are perspectives on medical practices. From an Indigenous perspective, there is often an incorporation of traditional medicine practices, with sacred and plant-based medicines (47). Traditional Indigenous medicine is holistic, encompassing physical, emotional, mental and spiritual health; treating each of these components of one's self is an essential part of improving health outcomes (47). Additionally, due to cultural differences, certain aspects of an Indigenous person's healthcare experience may differ in important ways, such as dietary preferences, communication styles, family dynamics and culturally based responses and reactions to sensations such as pain (48). Being cared for by family and close friends is also preferable. Part of the reason why familial involvement is seen as important is because it allows traditional Indigenous values that involve family, reciprocity, and respect to be honoured in the medical process (44). Furthermore, experiences that are often considered to be concerning or problematic from a Western perspective may be viewed differently through an Indigenous lens. For instance, while memory loss is often seen as tragic from a Western perspective, it may be regarded as part of a rite of passage that brings one closer to the Creator when viewed from an Indigenous perspective (44).

According to the Ontario Centre for Learning, Research and Innovation in long-term care, an ideal Indigenous long-term care facility must be located in close proximity to Indigenous communities, and must be designed to look and feel like a home (e.g., private rooms, comfortable living space) and not an institution (44). Multiple levels of care (e.g., acute and hospice care) need to be offered, while services and programs must have Indigenous involvement, input, and control. Regular training must also be provided to ensure that staff have the knowledge required to care for the Indigenous community in a way that respects their values, beliefs, and preferences. Traditional ceremonies such as smudging, as well as space to allow families and community members to visit, must also be supported. These criteria were developed in consultation with multiple Indigenous groups and individuals involved in Ontario's long-term care system (44). These individuals and groups have a variety of roles, including program directors, advisors, administrators, staff, residents and family members.

The lack of culturally inclusive live-in programming for Indigenous peoples, as well as the escalating issue of substantial wait times to access long-term care, may negatively affect Indigenous experiences in Ontario's healthcare system. Issues such as data gaps, the absence of ethnic identifiers within databases, and concerns about privacy and confidentiality are already prominent themes of the Indigenous healthcare experience, both within and outside the long-term care context (25,49). These issues contribute to a significant gap regarding Indigenous health information, which influences the adequacy of all types of care that Indigenous individuals receive in the Canadian healthcare system. The existence and growth of this gap is an ethical issue when considering equitable access to care for Indigenous peoples, since long wait times may be perceived as a denial of care (50). In addition, despite the increased focus on person-centred care, Indigenous peoples continue to experience negative health outcomes due to abuse and discrimination in healthcare settings (49). Although person-centred practices are supposed to provide respectful and holistic care for each individual, some healthcare providers contribute to the neglect of Indigenous residents by exhibiting behaviours that fail to promote cultural safety, contributing to the belief amongst patients that providers do not care about their values or wishes (49).

The above circumstance justifies the call for the creation of additional culturally inclusive long-term care services for Indigenous people who live in Ontario and require support. The province has a responsibility to ensure that the long-term care experience for Indigenous residents in Ontario aligns with their cultural preferences and beliefs since their needs and interpretation of long-term care may differ in important ways from some Western perspectives. Given our increasing aging population, the lack of culturally inclusive live-in long-term care homes can be seen as a denial of culturally inclusive care in general; this contradicts the call in the TRC to recognize the use and value of Indigenous healing practices, as well as collaboration with Indigenous healers and elders (51).

THE IMPORTANCE OF INDIGENOUS LONG-TERM CARE

Despite comprising a small proportion of Ontario's overall population, it is essential that Indigenous peoples are rightfully represented in the long-term care system. Not only is it an injustice that Indigenous peoples do not have access to proper representation and care, but this absence is detrimental to their overall health (52). The most important determinant of Indigenous health is colonialism, which stems from the ongoing effects of assimilation through historically oppressive systems such as residential schools (26). The residential school system forced assimilation upon Indigenous children by removing them

from their homes. Children experienced physical, emotional, and sexual abuse, and they were violently punished for speaking Indigenous languages. The spread of infectious disease and death also occurred (26). Ultimately, children were denied the opportunity to develop and experience Indigenous traditions, thus resulting in the destruction of Indigenous cultures, languages, and identities (26). The traumas that Indigenous peoples endured are directly linked to current health statuses and outcomes, resulting in an increased burden of illness and related inequities (26).

In order to provide proper representation and care, it is essential that care is culturally safe. Without this, the vicious cycle of colonization and Western privilege will continue through the legislated dominance of colonial languages and cultural practices (52). If Ontario's long-term care system remains the same, with the absence of Indigenous traditions, languages, and perspectives, then there is a very real risk that Indigenous residents will be re-traumatized.

A positive correlation exists between accommodating different cultures and improved overall health (44), whereas a lack of culturally appropriate care can act as a barrier when it comes to Indigenous peoples receiving necessary healthcare (53). If an individual enters a long-term care home that does not accept or represent their culture, then they may experience social and spiritual isolation, distress, malnourishment, alienation, and preventable health consequences due to a lack of effective communication (44). Cultural humility, cultural responsiveness (e.g., creating meaningful relationships through cultural connections), and cultural safety are integral to supporting Indigenous residents' spiritual, physical, mental, and emotional health (44). Providing culturally safe care to the Indigenous population is the best method of ensuring that the care being provided is ethically defensible.

Additionally, due to Canada's complex history with Indigenous peoples, there is moral obligation to ensure compliance with the TRC recommendations. Within the Commission's calls to action there are numerous calls related to the health of Indigenous peoples in Canada (51). Two are of particular importance in the context of Indigenous long-term care, i.e., Calls 22 and 23, which ask for the recognition of traditional healing practices, an increase in Indigenous employees in the healthcare field, and the delivery of "cultural competency training" (51). Additionally, the Commission called for the allocation of funding to continue and maintain assisted living programs, as well as to further develop the provision of long-term care services (54).

To acknowledge Canada's past with Indigenous peoples and to work towards repairing this relationship, it is vital that within Ontario and Canada, strong efforts are made to comply with these calls to action and be operationalized through specific budget proposals. Not only would complying with the recommendations outlined by the Commission improve the relationship between Indigenous peoples and the rest of the nation, but it would also assist in the improvement of Indigenous health.

NEXT STEPS

It is clear that significant improvements need to be made to Ontario's long-term care system in order to fulfill our ethical responsibility to provide culturally inclusive care in accordance with the TRC recommendations. One of the most important changes that needs to occur is the creation of more culturally inclusive live-in Indigenous long-term care facilities. In 2018, the province announced that an additional five-hundred long-term care beds for Indigenous peoples were being created (55). The aim is to make these beds available by 2022, along with an increase in nurses and care (55). Additionally, these beds will be distributed across multiple Indigenous healthcare facilities located in regions throughout the province. Although this outlined plan is beneficial for Indigenous peoples in Ontario, the additional services being opened in 2022 may be affected by long wait times for admission, as the addition of five-hundred beds can make only a small impact on the current waitlist of over 94,000 Ontarians.

Another change that must occur is that current care in non-Indigenous long-term care homes should be provided in a culturally safe manner. In order to complete this task, Ontario has started to make some policy changes. For instance, the Ontario Aboriginal Health Policy states that "traditional approaches to wellness" ought to be recognized, respected and protected from government regulation, as they enhance and complement healing, as well as the effectiveness of programs and services throughout the health system for Indigenous individuals (47). However, due to a dominant discourse of inferiority of Indigenous traditions and culture, depicted through past attempts of assimilation by the Canadian government and the lack of Indigenous inclusivity beyond the realm of social activities (48), these approaches to care have not been fully internalised into the Canadian healthcare system (47). Furthermore, Canada's history of racism, assimilation and reluctance to accept traditional Indigenous healing practices has led some Indigenous peoples to not disclose their traditions and practices with the Western healthcare system (i.e., to avoid being stigmatized), thus contributing to a negative healthcare experience for many Indigenous peoples in Ontario (47). In order to address these issues and ensure the provision of culturally inclusive care, the TRC Calls related to long-term care need to be answered.

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