

Improving preventive screening with Indigenous peoples

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Aboriginal women, for example, have expressed concern that epidemiological risk profiles for cervical cancer used in public health campaigns could further stigmatize aboriginal women as lascivious and irresponsible. Instead, analyses are needed that recognize that high rate of cervical cancer (among other illnesses) can no longer be blamed on women's high-risk status, nor can low rates of participation in screening programmes be attributed to cultural issues. Rather, these rates are perhaps equally indicative of women's avoidance of a health system that is not culturally safe and that does little to acknowledge or counter patterns of individual or institutional discrimination.

Annette J. Browne and Jo-Anne Fiske¹

Case

A 29-year-old Cree woman was recently welcomed into your family practice. You are meeting her for the first time, so you inquire if she needs anything in particular. She is homesick since she is not able to see her family and her community as much as she wishes. She is physically well and only needs a refill for birth control pills. You question her about her sexual habits, the number of partners she had, if she uses drugs or alcohol on a regular basis, and if she was recently tested for sexually transmitted infections. You are surprised to learn that she has never had a Papanicolaou test. You explain why Pap tests are done and how they can prevent cervical cancer. You note that as an Indigenous woman she is considered to be at high risk. You believe that the discussion is somewhat one sided. She politely declines the test. After she leaves, you believe that even though the clinical encounter was medically correct, the interaction did not feel right.

First Peoples, but second-class health care?

Across Canada, Indigenous peoples have poorer health² than non-Indigenous populations, as shown by data on chronic health conditions, avoidable mortality, suicide, substance abuse, and smoking rates^{3,4}; this leads to Indigenous peoples having a shorter life expectancy at birth—by 5 to 11 years—than the rest of the Canadian population.^{5,6} Indigenous peoples suffer from persistent inequity of access to care and heavier burden of preventable disease. In a recent publication documenting the association between Indigenous identity and poor postoperative survival,⁶ the authors raised questions about differences in disease stage at initial presentation and referral patterns.

When it comes to cancer, both Indigenous men and women have poor survival rates.⁷⁻⁹ Family physicians need to be aware that cancer diagnoses are often delayed, resulting in a heavier burden of morbidity and mortality in Indigenous populations. Scarce and conflicting data exist on the participation of Indigenous peoples in screening programs¹⁰⁻¹³; some have speculated that various reasons, such as accessibility or acceptability of screening programs, may lead to lower participation among Indigenous peoples.¹⁴⁻¹⁷

In tightly knit communities, this burden is often more socially meaningful as it will affect a friend or relative. Their stories and experiences of care are a reality shared with other members of the community.¹⁸ For cancer, the relative prevalence of advanced disease may make it appear incurable, reinforcing cancer stigmatization and fears. Too often, a cancer diagnosis is perceived as a death sentence, leading many patients to not want to look for it. This results in patients avoiding cancer screening or not wanting to seek medical attention when there are symptoms suggestive of cancer.^{12,15,19}

Key points

- ▶ Indigenous populations face challenges and barriers when accessing health care. Many aspects of a medical encounter can trigger trauma from past and historical health care experiences, provoking distrust and apprehension. Barriers to preventive care and screening are increased by assumptions built on the stereotypes that Indigenous patients are at “high risk” of bad health behaviour.
- ▶ Health care decision making in Indigenous populations can often include other family members, Elders, healing circles, and traditional healers. Family physicians providing care to Indigenous populations need to be aware of these traditional decision-making processes, as they may need to be included in discussions of benefits and harms of preventive interventions.
- ▶ Engaging Indigenous peoples and communities in screening programs requires trust, recognition of the historical and emotional issues related to past health care experiences, and genuine commitment for change.

Screening programs and recommendations are poorly adapted to Indigenous realities

Guideline-based screening (particularly cancer guidelines) is poorly adapted to the reality and preferences of Indigenous peoples. **Figure 1**,^{10,12,13,17,20-22} which is inspired by the conceptual framework of access to health care developed by Levesque et al,²⁰ depicts a cycle of documented pitfalls and barriers to accessing health care experienced by Indigenous people. The difficulties experienced by Indigenous patients often include the lack of appropriate and culturally tailored educational materials or advertising, inappropriate sample collection methods, physical barriers to accessing health care and screening infrastructures, limited local availability of primary care providers, and difficulties gaining entry into the system rapidly when diagnosed.²⁰ Also, there is difficulty accessing appropriate counseling, different challenges in ensuring adequate follow-up for an abnormal result, and confidentiality issues.^{10,12,13,17,20,21} The burden of colonialism and its impact, particularly for cervical cancer screening, also deserves specific consideration.^{9,17,22,23} These factors contribute to the preventive health care experience of Indigenous peoples and communities.

Often, regulations and restrictions on the scope of practice of allied health care professionals in remote communities limit their role in preventive health care and screening. For example, they are trained to perform the initial sampling, but cannot ensure proper follow-up without protocols to manage the results. Hence, follow-up of

screening results most often needs physician participation. Screening for cervical cancer and sexually transmitted infections are examples of these professional jurisdictional constraints.

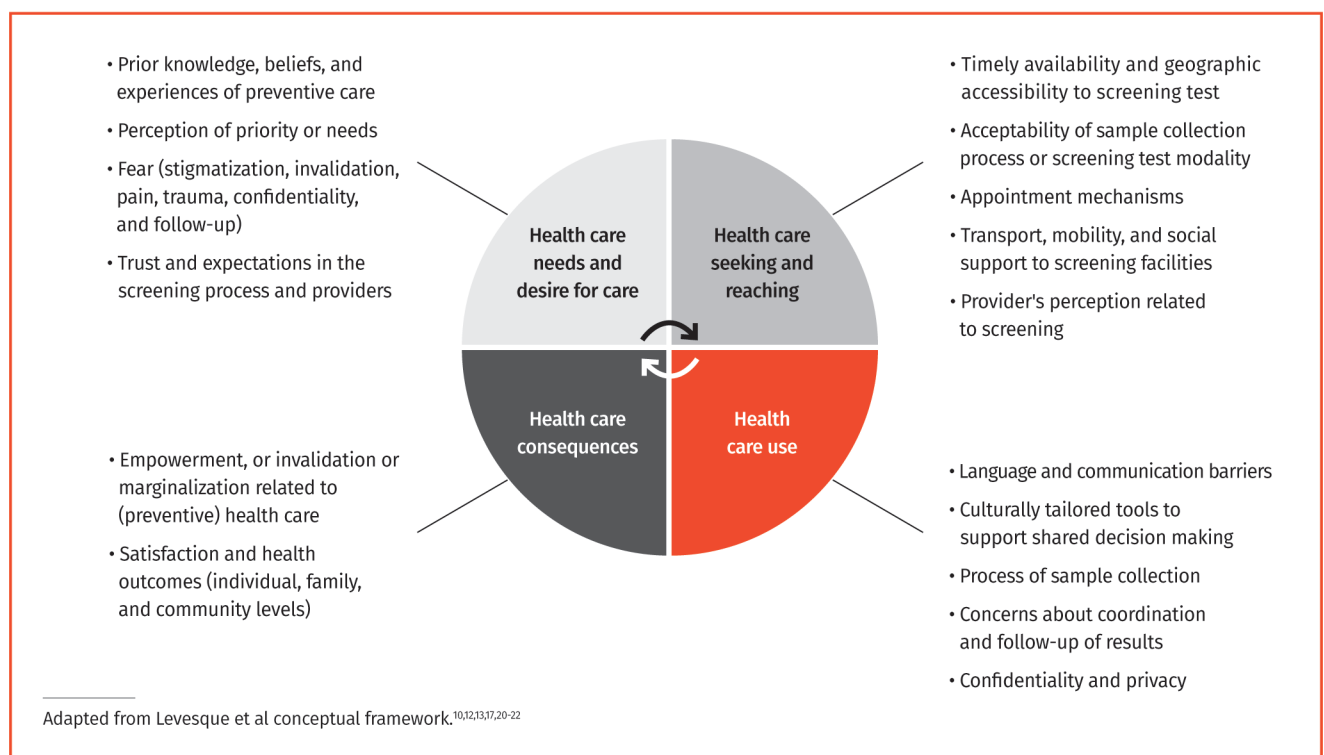
Continuity of care remains a major concern for follow-up of sensitive results. Many patients living remotely must leave significant others to undergo additional or complementary tests by seeking care outside their community—likely alone and often in a strange urban setting where they have had no previous experience and no one to accompany them and guide them through the system and their experience of care. How can we ensure the processes assist patients and support them adequately?

Preventive care recommendations are not neutral

“Evidence-based” recommendations are not neutral. They reflect the reality of modern-day colonialism in health care where “science” is often used to legitimize the superiority of one epistemology over another.²⁴ Recommendations presented by health care professionals as the “standard of care” may invalidate traditional wisdom of self-care. The message is even harder when the burden of colonialism is placed on the shoulders of Indigenous communities who face persistent inequity in the social determinants of health.

Physicians must never forget that medicine also operates as a system of power.²⁵ For example, an Indigenous

Figure 1. Circle of pitfalls and barriers to accessing preventive health care and screening



woman shared her story with us of being instructed not to eat traditional food (moose meat, in particular) when she was hospitalized for weeks because of complications during her pregnancy. Her iron levels, perfect when she arrived at the hospital, declined enough to require supplementation because of her hospital diet. This is an anecdote, but for Indigenous peoples, anecdotes become bricks, building a wall separating them from the rest of the population. In addition, the messenger is as important as the message, because recommendations do not function in a cultural vacuum. Bernard Roy, an anthropologist nurse who worked with the Innu people for more than 20 years, recalls that one woman trying to improve her health by eating lettuce had to deal with resentful comments from her own mother, who remarked that she never thought she would see her daughter eating like a White person.²⁶

Colonialism is embedded in the practice of medicine

Physicians are trained to identify, assess, and address risk factors. We constantly attempt to make decisions by evaluating the risk and prognosis for patients. Yet, when it comes to Indigenous health, what might be a simple “probabilistic approach” of medicine or preventive care may convey powerful and long-standing stereotypes. These stereotypes are informed and reinforced by decades of media coverage, policy, and research conducted without the involvement, perspectives, and consent of Indigenous communities.²⁷⁻²⁹ Science was embedded insidiously in our society and has contributed to shaping epidemiologic risk profiles. In addition, the probabilistic approach may unconsciously aggregate “being Indigenous” with “being at high risk” (ie, at high risk of substance abuse disorders, bad parenting, lascivious or deviant sexual behaviour, and more generally, bad health or bad habits).^{25,30,31} As such, indigeneity itself may be considered an independent variable of clinical significance when it comes to baseline risk of disease, preventing health care professionals from recognizing and addressing the contextual factors that are the real cause. Unconsciously, this can mislead our clinical judgment and behaviour and harm patients in ways that extend well beyond the clinical encounter.^{25,32} This is what McGibbon calls the “cycle of oppression” (Figure 2).³³⁻³⁵ Starting from biased information and leading to stereotype, health care professionals enter the clinical encounter with prejudice that may impact their actions and produce differential treatment.

Many, if not most, Indigenous people in Canada experience racism on a recurring basis.² As such, they often come into a health care setting with the expectation of poor treatment.^{32,36} Indigenous people’s responses may lead to feelings of exclusion, defensive attitudes, and avoidance of care.^{32,37} This avoidance activates delays in consultation, missed appointments, and missed interventions, leading to more severe disease at time of diagnosis,

which paradoxically reinforces stereotypes when patients and health care providers finally meet. This dynamic extends well beyond the walls of hospitals. The patient’s experience resonates in their family and their whole community. What happens to any one of them, happens to the whole community, while what happens to the community is also a part of each patient’s storyline.

Strategies to improve culturally safe screening

Acknowledging the limitations of the body of literature on cancer screening and other preventive care among Indigenous populations, very little attention seems to have been given to the importance of shared decision making as an empowerment tool. Screening per se should not be an end, but rather an occasion for a conversation between health care professionals and their patients, allowing them to discuss their values and preferences for their health. Thus, focusing on building a therapeutic relationship with an Indigenous person is critical—rather than aiming to check all recommended screening tests upon first encounter in an environment that is often seen as unwelcoming.^{32,38,39} In many cases, Indigenous patients may wish to discuss screening (or other medical decisions, for that matter) with their close family members or respected Elders in the community before agreeing with the suggested plan. Critically, certain specific aspects may be taboo, such as those dealing with sexual matters. Cervical cancer screening is a particularly sensitive matter, as it targets the power and intimacy of Indigenous women. All considerations being made show the gendered impact of colonial racism.⁴⁰

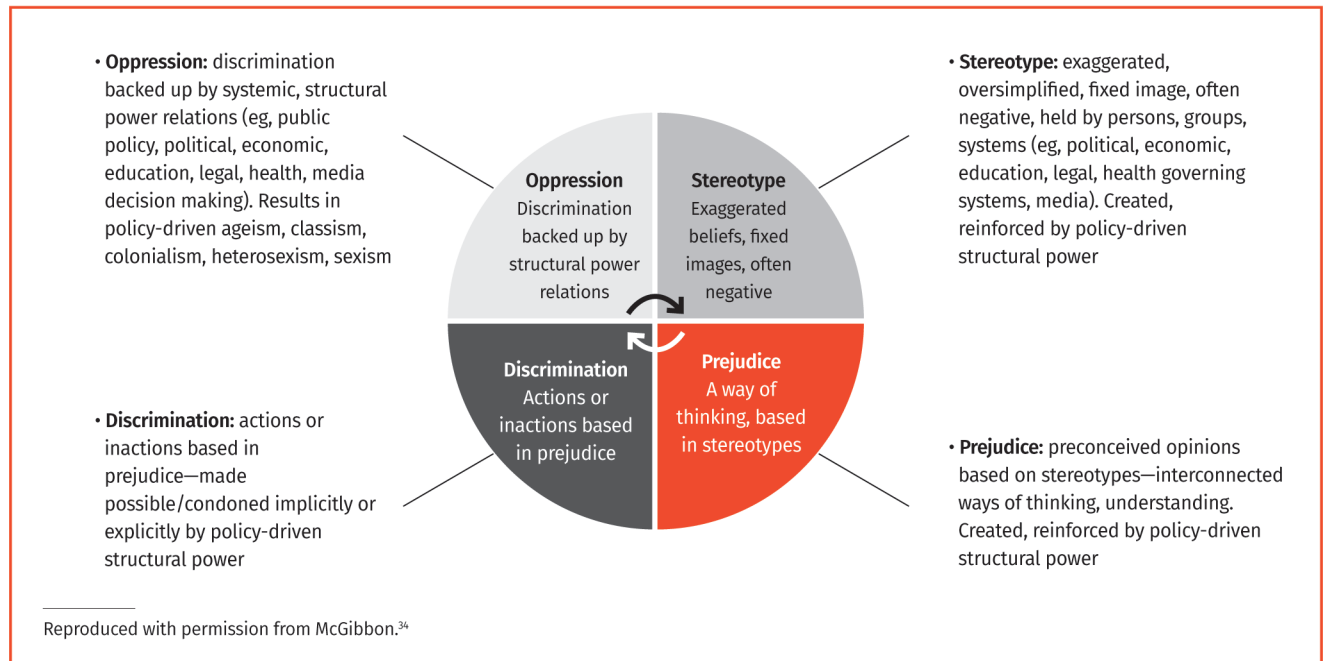
Trust and time—2 prerequisites for conversation—are often lacking. It is important to not just have more Indigenous patients screened for cancer, but to involve them in the conversation to decide whether and when they wish to undergo screening.

Cultural safety can be achieved only through meaningful participation in decision making, which involves promoting active participation in health care decisions and demonstrating true commitment and care for patients and their families.³¹

Returning to the case scenario, the encounter was “medically” appropriate. Still, something went wrong, or was missing. Could things have been done differently? The following are some strategies for culturally safe practices in preventive care:

Foundation of trust. Preventive care and practice requires many elements to be in place. The first is building trust with the individual by having an active awareness of their community context. There is no such thing as “trust at first sight.” No one can expect patients to trust medical personnel at the first meeting. Trust takes time to develop and is based on providing good and genuine care, initially for simple matters or relief of immediate pain, and subsequently for more complex matters.

Figure 2. Cycle of oppression



Linking services to Indigenous communities. Health professionals need to change the way they offer services to Indigenous people and communities to build a genuine link with communities and to foster continuity of care that respects and considers the specific living context of Indigenous people. The College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada have both released guidelines on how the CanMEDS framework relates to health care values important to Indigenous peoples.^{41,42}

Self-reflective practice. Providing high-quality care requires self-reflection in clinical practice and explicit attention to power relations between service users and providers.² As discussed earlier, these power dynamics and past experiences of racism influence and frame clinical interactions, including preventive care practices.

Self-reflection should tackle the question of implicit bias. Implicit biases are unconscious inclinations to prefer, favour, or neglect something that are absorbed from the environment in which one was raised.⁴³ Everyone has implicit biases. Available data suggest that they may impact clinical reasoning and judgment.^{41,44-46} As a key example, while the subject of racism in health care has been extensively researched in the United States,^{44,45} it has only started to be explored in Indigenous patients in Canada.⁴⁶ Some helpful self-reflective programs already exist: for example, San'yas Indigenous Cultural Safety Training delivered by the Provincial Health Services Authority in British Columbia is designed to enhance self-awareness and strengthen the skills of those interested in understanding and partnering with Indigenous peoples.⁴⁷

Empowering Indigenous people, families, and communities in prevention and screening. Many strategies can be used to support engagement of community members, knowledge transfer, and discussion on the relevance and value of screening (**Box 1**).^{5,9,16,22,48-50} Special attention should be directed toward strategies that can sustain shared decision making, such as healing circles, Elders' involvement, and Indigenous health care navigators. Consideration should also be given to the central caregiving role held by many Indigenous women who traditionally were the bearers of health wisdom. Acknowledging that health information may be shared differently and more broadly among those within one's circle, physicians should validate any "family of the heart" members who can help a patient decide what is best for their health care and provide time and space to allow this process to ensue.⁵¹

Facilitating screening

Supporting shared decision making for screening remains only part of the solution, yet is key to creating a culturally safe environment of care. After the decision to screen has been made, barriers to access need specific solutions. The literature supports initiatives improving on-reserve screening services, mobile screening services, advanced training for service providers, and group transportation to fixed sites. Data on effectiveness are not yet available, but other initiatives such as social marketing campaigns, organized screening days, and media education are also promising options to explore within Indigenous communities.^{5,9,16,22,49,50}

Box 1. Strategies to support engagement of Indigenous community members in screening

- Provide access to relevant educational materials that are adapted to their realities and accessible in local languages
- Seek support in the community for the presence of a community worker able to ease the discussion of complex medical issues in the community's native language
- Promote and empower women's roles as mothers and primary caregivers
- Dedicate resources to hiring of a "navigator" to support patients in the whole experience of care. Train and support health layperson advisors to do home visits to interact with patients
- Recognize the value and importance of having an older relative with the patient to discuss screening and preventive care during the consultation
- Acknowledge that patients may need time to assimilate information and that the decision to screen does not need to be made on the spot
- Encourage talking circles composed of Elders or survivors where positive stories of successful screening can be discussed and commented upon
- Use different reminders to engage with the screening program (eg, text messages [if accessible in the community], community laboratory drop, telephone follow-up by a community member to discuss potential barriers)

Data from Zhu,⁵ Maar et al,⁹ Zehbe et al,¹⁶ O'Brien et al,²² Gifford et al,⁴⁸ Browne et al,⁴⁹ Cancer Care Ontario.⁵⁰

Conclusion

Behaviour, expectations, attitudes, and gestures of health care providers most often perpetuate inequities and stereotypes that originate from colonization. These continue to undermine relationships with Indigenous patients and communities. Preventive health care, guidelines, and practices seldom acknowledge the influence of historical trauma. They differentiate cultural practices from what is considered the "standard of care." They often fail to recognize the strengths of Indigenous peoples and their ways of knowing, as well as the specific and systemic conditions Indigenous peoples face. Strategies to address these issues and to provide culturally safe preventive care are available to health care professionals (see suggested reading).

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Competing interests

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Suggested reading

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