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CASE 10

Lost in Translation: Developing Strategies for Indigenous People who have Cancer, Limited English Proficiency, and Limited Health Literacy

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Six Nations of the Grand River is a rural First Nations reserve located approximately an hour and a half from the busy city of Toronto, Ontario. It is also home to Dorthey, one of the few remaining fluent Mohawk language speakers in the territory, and her daughter Sarah. Dorthey is not bilingual; she speaks predominately Mohawk and understands some English. She believes in traditional ways of healing and is skeptical and afraid of Westernized health care. However, her daughter Sarah believes the two forms of care can work together.

In April 2020, just one month after the Ontario government declared a state of emergency because of the global COVID-19 pandemic, Dorthey received a devastating disease diagnosis. In her 70th year, she had been referred to Princess Margaret Cancer Centre in Toronto to undergo cancer testing. She was diagnosed with stage 3 breast cancer and had to start a treatment and care plan that would involve going to the hospital for weekly chemotherapy and radiation treatments. However, because of the current pandemic, there were new restrictions and guidelines in place at the hospital.

On the day of her first appointment, Dorthey was collecting her belongings to bring to the hospital for the daunting day ahead of her. "Okay, it's time to go," Sarah said. "We don't want to be late."

Sarah made sure to give her mother an iPad so she could call her and listen in on her mother's appointments. Because of COVID-19 restrictions, Sarah was not allowed in the hospital and Dorthey had to go alone. Sarah made sure to explain the basics to her mother, but she was still a bit unsure about how to use it.

As Sarah pulled up to the hospital, Dorthey explained how scared she was. "I don't want to go in by myself," she said in her traditional language.

"It will be okay," said Sarah. Dorthey got out of the car and was escorted into the hospital where she was now alone and afraid. She did not speak English very well or understand what was happening around her. She was taken to her hospital room where she was greeted by a nurse and a doctor who explained more about the tests and the treatment plan ahead of her.

With all the activity going on around her, Dorthey had forgotten all about the iPad Sarah had given her. She was still unsure how to use it as it was all new to her.



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Dorthey was scared to ask questions and had a limited understanding about her diagnosis and treatment plan. She was fairly confused and did not know what to do.

Halfway through her first chemotherapy treatment, she was feeling weak and fatigued. A nurse walked by and Dorthey said, "Ohné:ka." The nurse turned around with a confused look.

"What did you say?" she asked.

Dorthey replied, "Ohné:ka."

Just then, Rebecca Smith, the Indigenous Patient Navigator, walked by and overheard the conversation. She recognized the word because she too spoke the Mohawk language. She looked at the nurse and said, "She's asking for water, could you get her some please?"

Rebecca turned to Dorthey and smiled. She explained in the Mohawk language that water was on its way, so Dorthey would understand. Dorthey's sense of relief showed on her face.

Rebecca introduced herself as the Indigenous Patient Navigator and continued speaking Mohawk to ask Dorthey if she needed help. This was the first time Dorthey felt a sense of security. Rebecca continued to explain to Dorthey more about the medicine she was being given and how it would help her. She showed Dorthey how to set up her iPad so they could get in touch with Sarah, and she continued to sit with her and talk to her for the remainder of her treatment.

As the Indigenous Patient Navigator at the hospital, Rebeca was puzzled. At the time, the only way for patients to access the navigator program was to reach out. Rebecca realized that without a system to connect patients to the program, it will not be accessible to patients who are unaware of the service.

BACKGROUND

History of the Six Nations of the Grand River Territory

The Six Nations reserve comprises all six nations of the Haudenosaunee Confederacy – Mohawk, Cayuga, Seneca, Oneida, Tuscarora, and Onondaga peoples. It is the largest First Nations reserve in Canada by population, with 27,559 band members registered in 2019, and it is the second largest reserve by size (Groat, 2020). According to the Six Nations of the Grand River Development Corporation (2020), the territory spans more than 46,500 acres, but this represents only 5% of the original land promised in the 1784 Haldimand Treaty.

Many people residing throughout the territory still use the traditional languages to communicate, although few truly fluent speakers remain. The main languages spoken are Cayuga and Mohawk, and both languages are taught at the seven elementary schools on the reserve. Traditional culture is a way of life, with ceremonies continuing to be practised in homes and longhouses throughout the year. Many First Nations people believe in traditional ways of healing and view health through a holistic lens that treats the mind and body as one. Traditional ways of healing can include traditional ceremonies, and the use of plant-based medicine and land-based healing as ways of dealing with sickness, whether physical or mental.

The people of the Six Nations have a complicated history because they suffered through European colonization and assimilation. The longest-running residential school in Ontario was located just west of the reserve in the city of Brantford (Groat, 2020), and operated from 1831

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until 1996. The existence of these schools is one of the root causes of much of the mistrust, fear, and anger felt by the local First Nations people regarding Western ways of learning. Residential schools were established by the Government of Canada to "kill the Indian in the child" and force Indigenous children to assimilate into Western society (National Centre for Truth and Reconciliation, 2015). The experiences of the Indigenous students who were forced to attend these schools have caused years of intergenerational trauma and negative health impacts for many First Nations people.

Two-Eyed Seeing

In the fall of 2004, Elder Albert Marshall began to use the term Two-Eyed Seeing (Institute for Integrative Science and Health, n.d.). Two-Eyed Seeing is a framework that balances the traditional Indigenous ways of knowing with Westernized ways of knowing (Bartlett et al., 2012). It can be described as learning to see with one eye, using an Indigenous lens and way of knowing, and learning to see with the other eye, using a Westernized lens and way of knowing, and then learning to use both together (Institute for Integrative Science and Health, n.d.). This is an important approach for Indigenous people because colonization has pushed them into a Westernized world. This framework and the overlap and interconnectedness of both ways of knowing can be seen in Exhibit 1 (Institute for Integrative Science and Health, n.d.).

In terms of its application to cancer care for Indigenous people, Two-Eyed Seeing can be used to create a treatment plan using the patient's traditional ways along with Westernized approaches. Two-Eyed Seeing brings together the best of both worlds to produce the optimal patient outcome. It beneficially ties together two cultures and ways of knowing by integrating traditional Indigenous knowledge with Western medicine.

This process does have the potential to complicate care and treatment. Ultimately if there is a trusting relationship between patient and health care provider, then they are more likely to have clearer lines of communication. However, if there is no relationship built or no understanding, the patient may seek traditional healing on their own and potentially impact their course of Westernized treatment and care. This can be avoided by the healthcare provider taking the time to be patient, understand the needs and wants of their patient, and working in conjunction with what they want. Taking the time to get to know a patient can create a much more trusting relationship and help establish communication. In order to understand patients, some homework might be required by the health care provider, such as a talk with an elder from the community or some research on the internet.

About the Princess Margaret Cancer Centre

The Princess Margaret Cancer Centre is a world-renowned hospital leading the way in cancer research. The Centre has 12 site groups and 24 specialty clinics that allow more than 3,000 employees to see and treat over 1,000 patients each day (University Health Network, 2020). The Princess Margaret Cancer Centre continues to be on the frontiers of medical, surgical, and radiation oncology through ongoing research, education, and innovations (University Health Network, 2020). The Centre has taken actions to ensure the highest standards for patient care and ensures the best practices in patient care are applied throughout daily work.

Through ongoing research, the Princess Margaret Cancer Centre is transforming the hospital into a friendlier and more inclusive environment. By establishing plain language signage, information, and education programs, the hospital is becoming an easier place to navigate for patients, caregivers, and visitors.

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The Centre offers an array of amenities and inpatient and outpatient programs. The hospital has activity and relaxation programs, a patient and family library, an Indigenous Council, a child care centre, and food, retail, internet, phone, and television services (University Health Network, 2020). The Indigenous Council has a main goal of educating the community outside and within the hospital setting about past and present issues affecting Indigenous people.

The COVID-19 Pandemic and Cancer Care

In January 2020, a new virus was gaining recognition around the world (Government of Canada, 2020). COVID-19 is the disease caused by the SARS-CoV-2 coronavirus, a member of a large family of viruses (Government of Canada, 2020). In March 2020, the World Health Organization officially declared COVID-19 a global pandemic (Government of Canada, 2020). COVID-19 has permanently changed how the world works. Provincially, in March of 2020 only those deemed essential or frontline workers were able to remain open. To name a few, this included emergency responders like fire, police, and paramedics, as well as nurses, doctors, etc. Most businesses were either shut down completely or reverted to curbside pick-up and delivery. This lockdown was in place until the provincial government came up with a plan on how to move forward while protecting people from the virus as much as possible. At the onset of the COVID-19 pandemic, cancer testing and nonemergency surgeries were initially rescheduled or postponed at Princess Margaret Cancer Center. In November 2020, Ontario then moved to a reopening pandemic plan, moving from stages 1-3 to a colour-coded system with ever-changing protocols and guidelines (see Exhibit 2).

In response to the global pandemic, Ontario's hospitals were forced to modify services to patients through the use of:

- Restricted appointments
- Masking policies
- No-visitor policies
- Covid-19 screening processes upon arrival
- Covid-19 onsite testing
- Virtual care
- Personal protective equipment (to ensure both patients, caregivers, and healthcare personnel are all properly protected)

Hospitals were given the green light to enter into a phased reopening during Phases 1 and 2 of Ontario's framework to open the province in early May 2020. The Princess Margaret Cancer Centre eased back into a more regular schedule of diagnostic testing, appointments, surgeries, and other procedures (University Health Network, 2020). This required the hospital to balance patient needs, services, and programming with the updated public health standards (University Health Network, 2020). Although the hospital did reopen, plans were made for a possible second wave of the pandemic.

After the province reached Phase 3 of its reopening plan in the summer months of 2020, health professionals switched to a colored coded approach to identify 'hotspots.' This meant that some parts of the province would be in a yellow (cautionary) phase while other cities and towns, like Toronto, would be classified as grey (locked down).

As predicted by public health professionals, there was a surge in Covid-19 positive cases in the fall and winter months. Complicating this more, Christmas and New Year's celebrations proved to be the biggest test. Health professionals started to see a rise in Covid-19 cases after the

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holidays, ultimately leading to the declaration of a provincial State of emergency for the second time.

SPECIFIC AREA OF INTEREST

Limited Health Literacy and Limited English Proficiency

Health literacy can be defined as people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgements and decisions in everyday life (Parker, 2009). Recognizing health literacy early in the patient process is essential to better identify patient needs. It needs to be addressed at both the patient level, in terms of their own understanding, as well as from a health perspective. A patient must first understand what is being said to them with clear messaging and plain language and the person explaining the message needs to be cognizant of their audience. Paasche-Orlow & Wolf (2007) use a conceptual causal model to show limited health literacy is directly related to poorer health outcomes (Exhibit 3). It is important to address limited health literacy because evidence shows adults with low health literacy have inferior health care and poorer health outcomes than those of the general population (Institute of Medicine, 2009). Adults with limited health literacy often know less about disease management and health-promoting behaviours, and they are less likely to use preventative services versus those with high health literacy (Institute of Medicine, 2009). Minimal attention has been given to researching the effects of limited health literacy and limited English proficiency on health outcomes, even though these limitations affect the health of a substantial number of people (Institute of Medicine, 2009). Recent research shows reduced health literacy not only generally leads to poorer health outcomes, but it is also an underestimated global public health problem (Paakkari & Okan, 2020).

In health care settings, health professionals use complex medical terminology, most of which is not well understood by the general population. Patients who have limited health literacy and limited English language skills are at an even greater disadvantage than the general population in understanding health-related concepts. Social and cultural determinants of health can be directly correlated with health literacy and English language proficiency. Racism, stereotypes, cultural identity, poverty, education, and access to health care are all factors that play a role in influencing health literacy and language proficiency (Paakkari & Okan, 2020).

In order to create positive impacts on society, this problem needs to be addressed by creating new strategies to improve health care, and by ensuring health information and health care meet the needs of the patients, caregivers, and the greater public (Institute of Medicine, 2009).

SPECIFIC PROBLEM OF DECISION

Dorthey is alone at the hospital and is still a bit confused about her care. The current COVID-19 pandemic has created barriers for her during her treatment. As an Indigenous woman, Dorthey is already at a disadvantage having to constantly deal with social determinants of health such as poverty, racism, and education/literacy. She is unable to have her daughter with her and her limited English language skills make it very difficult for her to stay positive and understand what is happening. When Rebecca met her, Dorthey was completing her first round of chemotherapy at the hospital. It was simple luck that Rebecca noticed Dorthey speaking the traditional Mohawk language halfway through her treatment and understood her needs. After Dorthey finished her treatment for the day, Rebecca went back to her office to reflect on what had happened. She wondered how she could make it easier for patients coming to the hospital to get in touch with the Indigenous Council and the Indigenous Patient Navigator. How could she facilitate this connection? How could the hospital do a better job at bringing more attention to

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the Indigenous Patient Navigator Program? Rebecca also wondered which approaches would be best for communicating with patients like Dorthey who have limited English and limited health knowledge. She started to write down some possible strategies. These included:

- Increasing hands-on care (i.e., bathing, eating, brushing teeth, physiotherapy)
- Augmenting the patient library with more Indigenous-specific educational materials
- Increasing community support and partnerships
- Involving a community translator
- Offering virtual support
- Using more visual aids and pictures (for cancer information, around the hospital)
- Increasing Elder involvement in programs
- Employing more Indigenous hospital staff
- Ensuring frontline staff are aware of the Indigenous Patient Navigator Program through enhanced promotion, increased education, and cultural sensitivity training

Through this experience, Rebecca realized more specialized strategies need to be developed to meet Indigenous patient needs at the hospital. The Princess Margaret Cancer Centre and the Indigenous Council will continue to work together to be leaders in patient care and in developing more effective ways to connect Indigenous patients with appropriate patient navigators. Rebecca will contact other hospitals and Indigenous communities to put together a variety of possible strategies and programs to present to the Princess Margaret team at the next meeting with the hopes of implementing a new framework as soon as possible.

At the next meeting, Rebecca hopes to create a new Indigenous-led taskforce made up of herself, an Indigenous council representative, representatives from nearby hospitals, and an Indigenous elder. She hopes to receive input from a variety of stakeholders to create 'best practice' guidelines moving forward and to hear what others in the area are doing. She hopes to be able to have an open conversation and learn from each other on how best to move forward and create the best culturally sensitive framework as possible.

CONCLUSION

Dorthey was ultimately able to connect with Rebecca and build a trusting relationship with her, which helped her throughout her treatment. It simply involved having a friend to talk to, having someone who understood her and her specific needs, and having someone who was able to advocate for her and what she wanted in terms of her traditional ways of healing. She was able to advocate for her ways of healing and for the ability to communicate in her language. However, this relationship was stumbled upon accidentally. Had this not happened, Dorthey would have been navigating her cancer treatment at the hospital all alone and it would have been completely different. And the next patient in similar circumstances might not be so lucky.

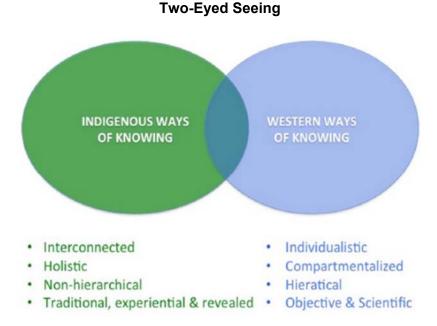
Unfortunately, a cancer diagnosis for patients who also have limited health literacy and limited English proficiency can directly correlate with negative health outcomes. The Indigenous lens used in health care treatments for First Nations people must also consider this reality. Often, Western medicine does not consider traditional views or alternate ways of healing. This is where cultural competency training is often overlooked in bigger institutions. From an Indigenous lens, healing looks different for everyone. Holistic healing is of great importance because one must heal mind, body, and spirit in order to be healthy versus the Westernized approach to healing which involves treating just the problem. In this case, Dorthey attended a Westernized institution which took her through the path of chemotherapy and it did not really consider who she was or where she came from. She was reluctant to receive care because she also wanted traditional

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healing. Often, Indigenous patients will go ahead with their own traditional medicines in conjunction with Westernized treatments. Therefore, it is important to have advocates and a clear patient-health care provider relationship, to ensure the best possible care and make sure everyone understands. Along with Westernized approaches to cancer care, the limited health literacy and limited English proficiency that often affects Indigenous people is also compounded by racism, cultural stereotypes, and lack of access to health care. Health care professionals need to ask their Indigenous patients questions to determine if they really understand what is happening and whether they can make informed decisions about their treatment. Using the Two-Eyed Seeing approach, health professionals can gain their patients' trust by incorporating both types of knowledge into one comprehensive treatment. There needs to be clear communication between the patient and health professional in order to do this. If there is not. steps need to be taken in order to build a trusting relationship. This may include an interpreter or having a conversation with a family doctor or community elder. Ultimately, hospitals in Westernized health care systems need to be aware of their patients' needs and give them the best resources possible. There must be enhanced programming and information for Indigenous people that is straightforward and easy to find and use. Ensuring that Indigenous people and other marginalized communities have greater access to targeted and appropriate health care resources and treatments will improve the health outcomes for these populations.

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EXHIBIT 1



Source: Carter et al., 2016. Adapted from Bartlett et al., 2010.

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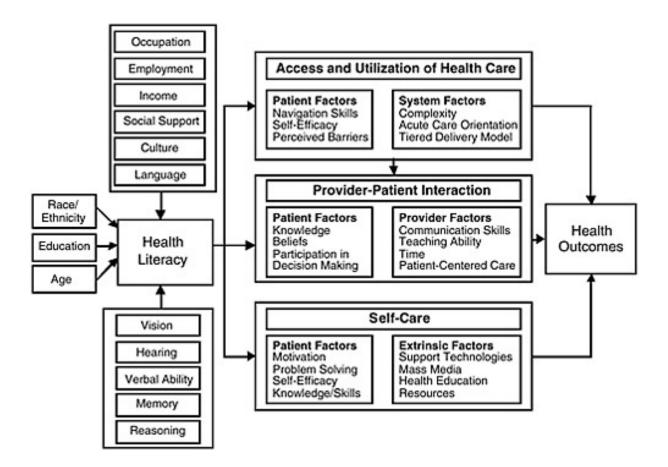
EXHIBIT 2 Ontario's Colour-Coded Covid-19 Framework

Framework: Adjusting and Tightening Public Health Measures



Source: Government of Ontario, 2020.

EXHIBIT 3 The Causal Pathway between Limited Health Literacy and Health Outcomes



Source: Paasche-Orlow & Wolf, 2007.

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INSTRUCTOR GUIDANCE

Lost in Translation: Developing Strategies for Indigenous People who have Cancer, Limited English Proficiency, and Limited Health Literacy

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BACKGROUND

Studies have documented that people who have limited health literacy and limited English proficiency often have challenges with all aspects of health care, including difficulties accessing health care, understanding medical information, making treatment decisions, taking prescriptions properly, and communicating with health care workers. People who have limited health literacy often have an overall negative outlook about health care, and they are less likely to seek help from health care providers or health programs, which can negatively affect their overall long-term health and lead to poorer health outcomes than those with high health literacy.

The main goals of this case are for the reader to understand limited English proficiency and health literacy in the context of health care for Indigenous populations, and to define and apply strategies to effectively communicate with these populations in a health care setting.

This case provides the reader with an array of information regarding Indigenous health issues and perspectives. It gives the reader the opportunity to assess a health care problem and identify the social and cultural determinants of health within it. Through the use of concept mapping, the reader will be pushed to explore the relationships between limited English proficiency, health literacy, and Indigenous knowledge and beliefs in a healthcare setting. It will challenge the reader to think critically about the situation and propose strategic interventions to break down communication barriers.

OBJECTIVES

- 1. Define health literacy.
- 2. Describe the importance of communicating clear treatment plans to patients who have limited English proficiency and limited health literacy.
- 3. Identify the social and cultural determinants of health faced by Indigenous cancer patients in health care settings.
- 4. Develop communication strategies for Indigenous cancer patients through the use of a concept map.

DISCUSSION QUESTIONS

1. How can a global pandemic affect hospital cancer care and potential impacts of a pandemic on patients who have cancer?



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- 2. What are some creative tools and/or strategies that can be used to communicate with patients who have limited English proficiency?
- 3. Are there particular barriers to working with Indigenous people in the health care setting? Why or why not?
- 4. What kind of community partnerships could be involved in creating an Indigenous-specific cancer care program?

KEYWORDS

Cancer; concept map; COVID-19; English proficiency; First Nations; health communication; health education; health literacy; Indigenous people; Mohawk language; pandemic; residential schools; traditional medicine/healing; Two-Eyed Seeing; The Causal Pathway.