Bridging the gap between two world views: Perspectives of an Indigenous nurse

Lianne Mantla-Look

"Do you find it hard to work there?"

It's a question I get asked a lot after telling people that I worked in my home community as a registered nurse. It can be challenging at times. Occasionally, a select few make it difficult by having unrealistic and unethical expectations of me such as requests for narcotics or sick notes. There are others who assume I'm going to tell my family about who I saw that day at work and what for. And finally, there are the people who make putting up with all the negative experiences worthwhile: The Elders. They are ecstatic about a Tłı̨chǫ-speaking nurse working in the community and they make my career a rewarding one. If I can use my first language to help people navigate their health care experience then I feel I've provided the best care to my patients and have done what most people cannot do. I embody the Tłı̨chǫ philosophy of "Being Strong Like Two People": I am able to function in both the traditional Tłı̨chǫ world and the mainstream Canadian world.

I was always considered the outlier or an anomaly in my community. I was a good student and I didn't live up to the stereotype of being from a small First Nations community. I didn't do drugs and waited until I was 21 to have my first alcoholic drink. I was conscious of my personal choices because of negative stereotypes about Native people. I graduated high school a year early, and went away to college and then university. Then, I began this incredible career in health care. I worked hard for what I accomplished, and though there were some people who were immensely proud of me, there were others who begrudged this hard-won success.

During my first month of work at the Behchokǫ̀ Community Health Centre, I called a woman Elder into my exam room from the waiting room. She seemed a little nervous and when I closed the exam room door, she asked me in Tłı̨chǫ: "Aren't you going to need an interpreter?" to which I replied in Tłı̨chǫ "What for? I can understand you just fine." The look on her face was priceless, she was so happy and so incredibly relieved! Then she laughed and said, "You're a Tłı̨chǫ person? I thought you were White!" We both laughed because, how funny was that? She asked who my parents were and after I explained whose daughter I was, we got on with her reason for coming to the health centre. She was so happy to be examined by a Tłı̨chǫ nurse and not have to go through an interpreter and explain through a third party the reason she was at the health centre that day. At the end of the visit, this Elder shook my hand and thanked me profusely and told me how happy she was to have a Tłı̨chǫ nurse in Behchokǫ̀. It was a humbling experience and probably the best day at work I've ever had.

The inability to speak English is a huge obstacle in accessing health care. Interpreters are commonplace in remote health centres for people who do not speak English, such as the Elders of the community. A language barrier can result in having incorrect or misleading information given to health care providers and to the patient. Patients can feel uncomfortable and unable to fully express themselves.

In my nursing practice, I've acted as the interpreter for doctors who treated people from my region. This was beneficial for the doctors because I was able to complete the history portion of their exam for them in Tłı̨chǫ and thus saved time while putting the patient at ease. Other discussions I have been involved with have been about code status – ["Code status" essentially means the type of emergency treatment a person would or would not receive if their heart or breathing were to stop] – and end-of-life care, where a person plans for a time when they cannot make decisions for themselves. It was during a discussion about one such issue that I noticed something rather alarming – family members interpreting for the patient withheld critical information from the patient regarding the patient's code status. The risks and benefits of CPR and intubation were explained to the interpreter (the family member) but the interpreter did not relay this information to the Elder, for example, that the risks of CPR include fractures to the rib, sternum and spine and CPR sometimes results in injuries to the liver and spleen, damaged airways, internal bleeding, heart contusions and pulmonary complications.

An example of this was when a Tłı̨chǫ Elder was admitted to hospital after having a stroke. Given the patient's age and severity of the stroke, the doctor wanted to have a family meeting to discuss the care plan and code status in the event of another stroke. The patient's son and daughter refused a medical interpreter and relayed the information to the patient. I was present as the witness for the doctor who did not know that I spoke the same language as the patient. The son told his father that if his heart stopped or he stopped breathing, the doctor was going to hook the patient up to a machine to heal the patient. The patient agreed and was ready to sign the consent form agreeing to be a full code – which meant that all resuscitative and aggressive curative treatment are provided. I pulled the doctor aside and informed him of the miscommunication and that the risks of being a "full code" were not properly explained at all to the patient. This family did not understand that relaying incorrect information to the patient was highly unethical and that they put their father and the doctor at risk. The end result was the doctor called a medical interpreter to be present and had the same discussion with everyone again.

When other situations like this arose, the doctor would often ask the family directly why they provided the patient with incorrect information. The answers usually included: "The patient is too weak or frail to deal with the situation" or "we don't want the patient to lose hope and get depressed" or "we don't want the patient to panic." Putting the burden of medical translation on families is unfair to both the families and the patient. It's unethical not to use a medical interpreter for consent and procedures. Doctors and nurses need to trust that their information is being relayed correctly.

Throughout my career, I have had the privilege of providing end-of-life care to many Elders and helping to guide families during the palliative process. I did this for my own family as well when an immediate family member died of cancer; it was then that I saw first-hand how challenging it was to navigate the medical system for my family, where for me it was second nature. I'm not sure if this is the case in other First Nations communities, but in my own professional and personal experience, cancer was always spoken about in hushed tones in my region. Typically, no one knows much about cancer except that it often leads to death.

There is no Tłı̨chǫ word for cancer. When I was growing up, cancer was described as "Tàda nàtso" which meant "strong disease," and then the official Tłı̨chǫ dictionary translation for cancer became "parasitic disease" or "gòo tàda."

As much as I respected my culture and our ways, I struggled internally to remain "neutral" whenever I had to care for a cancer patient from my region, because I believed in medicine and science. I struggled between who I was as a Tłı̨chǫ woman, and as a nurse who believed in science. In my region, at least, many people distrust Western medicine and seek out alternative cures for cancer. Too often, I've seen patients and families spend time and money trying to find a cure for cancer, losing valuable time with their loved ones. I became especially jaded when an immediate family member was diagnosed with stage 4 pancreatic cancer when they were 37. My family spent thousands of dollars looking for a cure and seeking help from traditional healers who were known to "cure cancer." I tried to make my family see that all of these interventions were going to cost us precious time that we had so little of already. But my arguments fell on deaf ears. We were given a prognosis of 4-6 months, much of which my immediate family member spent being driven all over Alberta trying to find medicine people to cure their late stage cancer. I hate to think of the lost time with their three children. By the time they gave up, my family member was getting weaker and weaker. They died just weeks after their 38th birthday, almost exactly four months after the diagnosis.

Then I received my own cancer diagnosis in 2015. I was 34 years old. What was supposed to have been an overnight trip to Edmonton with my husband became a week-long hospital stay. What do you do when your doctor calls you to tell you that you have cancer? First you cry and then ask you ask questions: What kind of cancer? What's the plan? Then you cry with your husband. You cry some more during your assessment with the surgeon who tells you the plan. You cry again as you call your mom to tell her that her youngest child was diagnosed with cancer eight years after her eldest succumbed to this terrible disease.

Despite being emotional about this sudden news, I was quite practical with my next steps. I notified my employer right away, I cancelled our flight home to Yellowknife, extended our hotel reservation and arranged for a friend to look after our pets. I believe it was my nursing education and years of experience that allowed me to accept the news initially. Then the reality set in and I became a patient with a tough pill to swallow. It took me several months over the course of my recovery to be okay with relinquishing my role as caregiver.

During my initial hospital stay, I had two gastroscopies and 53 biopsies taken from my stomach before being sent home to Yellowknife to await the biopsy results. A week later I received confirmation that I did indeed have stomach cancer. I would require the total removal of my stomach and surrounding lymph nodes as well as parts of my esophagus and intestines. It was not going to be a simple surgery or recovery, but my surgeon was confident that I would pull through. My surgery took approximately ten hours. The recovery was the most pain I had suffered in my life. Most of my life I've taken care of other people and this time it was me in the hospital bed. I did not know how to deal with it.

I hated every moment of being a patient, but tougher still was being a Tłı̨chǫ patient. I clashed with my mother about sharing my diagnosis with the rest of my region. When someone from the Tłı̨chǫ community becomes sick, everyone is supposed to be informed "for support," my mom said. At that point in what was to me a very new and difficult situation, I needed privacy. Therefore, I chose instead to tell my close friends and a couple of family members, rather than all 70 first cousins and their families. I requested that my relatives refrain from sharing anything on social media. I didn't want every Tłı̨chǫ citizen knowing my business. My mother could not understand it; for her it was not the Tłı̨chǫ way of doing things. Unlike a typical Indigenous patient, I was able to draw on my knowledge of health care to ask nurses to perform specific care tasks, and expected detailed information from my team. This experience caused me to wonder: How often are Indigenous patients given sub-par care when they are unable or afraid to speak up, especially if they aren't familiar with southern hospitals and are far from home and family?

As a frontline nurse, I always encouraged patients to advocate for themselves and to always ask questions about their care. When it came to my own care, I am not sure where I would be if I didn't push my doctors for that colonoscopy referral when I knew there was something wrong with me. Where would I be if the gastroenterologist hadn't ordered the gastroscopy as a precaution after he found three polyps – the same gastroscopy which led to the discovery of my cancer? Probably dead. My cancer was a slow-growing one that would not have presented itself until I began showing symptoms. The fact that my cancer was caught so early was a total fluke. Even the surgeon who did the first biopsy of my stomach said she "didn't think it was anything sinister." It was my own self-advocacy – a direct result of my nursing training and experience – that enabled me to receive the level of care that would directly contribute to early detection and survival.

It is critical that Indigenous patients be empowered and informed enough to begin advocating for themselves. For many, obtaining medical or nursing training is not an option; the chances of having a nurse who speaks their language fluently is rare to non-existent. How are health care providers supposed to provide the best care if they can't communicate with their patients? And how are patients supposed to communicate with health care workers when they aren't culturally safe and supported? We need to close linguistic and cultural communication gaps between Indigenous patients and the health care system. To do that, we need the system to better understand and work with Indigenous people to build trust. Trust is the first step in creating a system that better serves Indigenous communities in Canada.

So, how do we build trust?

We build trust by understanding culture and allowing there to be a place for differing cultural identities in the health care system. That can be through critical services like medical interpretation, but also through things like traditional foods and making room for ceremonies in care. We build trust not only by understanding the history and systemic biases that exist in health care but also by training health care workers to address their own internalized biases to build individual cultural competency.

Finally, we build trust by building up Indigenous people to enter careers in the health care system. This is a critical piece of the puzzle. My nursing education and knowledge of the health care system is what gave me the confidence to advocate for myself. Until people are seeing themselves reflected in the system, how can they fully trust it? And how do they see themselves in a system they can barely communicate in without a translator? How can they advocate for themselves? By encouraging and supporting Indigenous people to enter the health system, we can reduce perceived tensions between Indigenous ways of knowing and Western medicine. We can create a system where both complement each other. This would be a system that would truly serve Indigenous people and improve health across Canada. ◉

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