Sourabh Arora BSc, MD¹

Ayaz K Kurji BScH²

Matthew TS Tennant BA, MD, FRCSC¹

¹ Royal Alexandra Hospital, University of Alberta, Department of Ophthalmology, Edmonton, Alberta

² Queen's University School of Medicine, Kingston, Ontario

Dismantling Sociocultural Barriers to Eye Care with Tele-Ophthalmology: Lessons from an Alberta Cree Community

Abstract

Purpose: There are significant disparities in access to health care amongst Aboriginal Canadians. The purpose of this study was to determine whether tele-ophthalmology services, provided to Aboriginal Canadians in a culturally-sensitive community-based clinic, could overcome social and cultural barriers in ways that would be difficult in the traditional hospital-based setting.

Methods: The Aboriginal Diabetes Wellness Program of Alberta incorporates culturally-sensitive health-related activities and rituals as a component of a diabetic retinopathy tele-ophthalmology screening program. Metrics of program attendance were collected while stakeholders participated in a survey to identify barriers to healthcare delivery.

Results: Aboriginal patients, cultural liaison, nurses and program administrators revealed economic, geographic, social and cultural barriers to healthcare faced by Aboriginal people. It was found that the introduction of culturally-sensitive programs led to increased appointment attendance; from 25% to 85%. Involvement of Aboriginal nurses, inclusion of culturally-sensitive activities and participation in spiritual ceremonies led to qualitative accounts of increased patient satisfaction, trust towards the healthcare team and communication amongst participants.

Conclusions: A culturally-sensitive model of healthcare delivery in a community-based health clinic improved access to tele-ophthalmology services. This was demonstrated by increased attendance at appointments and increased satisfaction amongst patients.

Manuscript submitted 13th June, 2012

Manuscript accepted 18th March, 2013

Clin Invest Med 2013; 36 (2): E57-E63.

Correspondence to:

Matthew T.S. Tennant
University of Alberta
Department of Ophthalmology
400, 10924 - 107 Avenue
Edmonton, AB T5H 0X5
mtennant@ualberta.ca

A source of pride amongst Canadians is our universally accessible healthcare system; however, a visit to most Canadian Aboriginal communities will reinforce how many barriers still must be dismantled in order for Canada's healthcare system to live up to this ideal. Disparities in healthcare are the direct results of economic, geographic, social and cultural barriers [1]. The most effective healthcare interventions must be individually designed for and engage the community in question [2].

It is important to recognize that Aboriginal Canadians face many disparities when compared with non-Aboriginals, including lower high school graduation rates, higher unemployment rates, lower average household incomes, decreased life expectancies and less frequent consultation with family physicians [3]. Despite increased rates of diabetes and obesity, Aboriginal peoples tend to access diabetes and nutrition educational information less often than the general Canadian population [4]. In addition, Aboriginal Canadians report poor working conditions, unsafe communities and difficult access to food and water [5]. Cultural differences between Aboriginals and non-Aboriginal peoples may also have negative impacts on their social support networks [4,6].

"Tele-ophthalmology", a novel form of health care delivery that facilitates the provision of eye care remotely within the patients' community, is proving effective at overcoming multiple barriers to healthcare access across Canada [7]. In Alberta, tele-ophthalmology screening clinics are advertised on the radio, newspaper and amongst the Aboriginal reserves via member referrals. Nurses typically lead the clinics, which are held approximately once a month in remote communities throughout Northern Alberta. The screening consists of a medical history, vascular risk factor identification and stereoscopic digital fundus photography [8,9], coupled with the provision of basic diabetes education. The collected information and images are transmitted to ophthalmologists at the University of Alberta in Edmonton through proprietary software, Secure Diagnostic Imaging Ltd., after being uploaded by the clinic nurse. Using high-definition video monitors with stereoscopic viewing capabilities, ophthalmologists then review the case, diagnose any ocular pathology, especially diabetic retinopathy, and suggest a management plan (Figure 1). A report with recommendations is sent to the patient as well as their family doctor, and if the patient requires treatment, transportation to the hospital is arranged. Several studies have compared tele-ophthalmology approaches to traditional in-person examination or slide film photography and have concluded that tele-ophthalmology methods have high sensitivities and specificities in the identification of retinal diseases such as diabetic retinopathy [10-12].

FIGURE 1. Hands-on experience with the special technologies used in tele-ophthalmology

By considering the population's values, culture, existing infrastructure and day-to-day lives, a healthcare intervention may be molded to fit its niche in the most effective, and hence sustainable, way [13]. In 2009, the program administrators hypothesized that creating a social and cultural environment in a community clinic setting in keeping with traditional Aboriginal values would lead to increased utilization and satisfaction with the tele-ophthalmology services. This was in response to poor attendance for hospital-based eye screening and comments from healthcare staff that Aboriginal patients were not feeling at ease in the clinic setting. After two years of integrating a culturally-sensitive setting, a remote clinic serving patients from Wood Buffalo, a predominantly Cree community in Northern Alberta, was qualitatively analyzed. Interviews, metrics of participation and discussions with program administrators were employed. Herein, the findings from our qualitative and quantitative research and a literature review on how tele-ophthalmology is facilitating socio-culturally relevant care for Aboriginal communities, which may lead to improved access to quality eye care, are discussed.

Methods

Starting in 2009 a socio-culturally welcoming community level tele-ophthalmology clinic was created to provide eye-screening services for Aboriginal Canadians with diabetes. To overcome language barriers, nurses fluent in Cree were hired from the local communities. Religious/cultural artifacts were included in clinic screening protocols. Before and after every clinic, ceremonies were held under the guidance of an invited spiritual leader from the community. In the "Smudge" ceremony, smoke

from a burning plant (considered a traditional medicine) is spread over one's body with the goal of purification, thereby inviting health into the participant (Figure 2). Participants sat in an open circle to discuss physical, mental, spiritual and emotional health, challenges to overcome, and individual goals for healthy living. A teepee was set up outside the tele-ophthalmology clinic, where the attendees would often gather together to socialize and participate in more cultural activities (Figure 4). Nurses provided snacks, as traditional healers would do at their community-based gatherings. Activities such as bracelet-making were encouraged, with the order of the coloured beads helping the wearer to remember which medications to take and when.

Two years after instituting this culturally-sensitive model of health care delivery, our team conducted a qualitative satisfaction review of the program. From September to December 2012, our team participated in ground-level research of a community health clinic, entitled Aboriginal Diabetes Wellness Program (ADWP) serving Cree patients from Wood Buffalo, Alberta. The ADWP incorporates a tele-ophthalmology clinic with a focus on educating Aboriginal people about diabetes, healthy lifestyle choices while providing medical screening tests (Figure 3). For our qualitative analysis data was collected on attendance to the tele-ophthalmology clinic over the last two years. Interviews were held with attendees and stakeholders. This included five patients, two program administrators, one nurse from the hospital, one nurse from the remote clinic and one spiritual liaison of the Aboriginal community. Three separate clinics were attended to complete this process. A member of the research team experienced the clinic firsthand

FIGURE 2. Photos from previous ADWP clinics, including education and cultural activities

by following patients through the typical flow process and participated in the various culturally friendly activities, while observing the level of participation and enthusiasm of attendees. Using open-ended questions and discussion; we sought to better understand barriers to eye care amongst Aboriginal patients, as well as the reactions to the culturally sensitive approaches employed at the tele-ophthalmology clinic. After collecting responses to the interview questions, a thematic analysis was conducted with a focus on identifying barriers to care and how they were overcome. Frequently emphasized points from the interviews were highlighted (Table 1).

FIGURE 3. Diabetes education session within the ADWP clinic.

FIGURE 4. A teepee outside the ADWP where Aboriginals meet for rituals, discussion, advice from the "Elder"

TABLE 1. Select quotes from tele-ophthalmology program stakeholders

	Q1. Can you tell us about your experiences with a hospital based ophthalmology clinic, or other hospital based health clinic?	Q2. Attendance was very poor to the hospital based eye screening clinics. Why do you think that is?	Q3. Can you tell us about your experiences with the community-based tele-ophthalmology clinic?	Q4. In 2009, the tele-ophthalmology clinics were made more culturally sensitive. What do you think about this strategy?
Patient	"I live more than three hours away from the nearest hospital"	"I can't afford to take time off work, to get to the city. There are so many appointments"	"The nurses are all Aboriginal and so we can understand each other better"	"Smudge is part of our tradition and it helps us to openly discuss our health..."
Aboriginal Cultural Liaison	"The hospital is very intimidating to our people. We don't feel we are being treated fairly here, and we feel very alone."	"To feed the spirit, one must stay connected to nature, not be inside a hospital."	"Many more community members know about this clinic, mostly through word of mouth."	"This is a good way the hospital shows respect to our community and our way of life"
Program Administrator	"Attendance was very poor amongst Aboriginal patients. Some patients who made it to the hospital would then leave in the waiting room because they thought they were being mistreated."	"The Aboriginal community looks at traditional medicine differently. If an appointment conflicts with their cultural events, they won't show up."	"This was the best solution we could think of, and we got the idea from the Spiritual Liaisons who really understand the Aboriginal community"	"Attendance has really improved, but more importantly the conflicts have really settled. They want to be at the clinics now."
ADWP Nurses	"Patients would complain to me that they came all this way just to be told again they had to control their diet."	"We would talk with the patients on a personal level, and learn how difficult some of their economic situations were"	"At least this helps reduce some of the stress and pressures due to travelling so far"	"Attendance to the clinics increased largely due to familiarity, comfort, more time spent with a patient..."

The following questions were asked to survey participants:

- Q1. Can you tell us about your experiences with a hospital-based ophthalmology clinic or other hospital based health clinic?
- Q2. Attendance was very poor to the hospital-based eye screening clinics. Why do you think that was?
- Q3. Can you tell us about your experiences with the community-based tele-ophthalmology clinic?
- Q4. In 2009, the tele-ophthalmology clinics were made more culturally-sensitive. What do you think about this strategy?

Results

The strategy of combating cultural disparities in a geographically remote ophthalmology clinic was undertaken in 2009. Based on clinic attendance records, 20% of referred Aboriginal patients attended appointments before the tele-ophthalmology cultural interventions were instituted in 2009. Within the first year, the attendance rate increased to 50%. As the program became more socio-culturally relevant, with added activities and hiring of more Aboriginal nurses, the attendance rate increased to 85% by 2011. Additionally, the average number of

patients attending per ADWP clinic rose from five to eighteen. Patient satisfactions, enthusiasm for educational activities and adherence to advice about lifestyle modifications to control diabetes were felt to be considerably higher following introduction of the program as indicated by nurses who had been involved prior to the program's inception.

A variety of factors were identified during the interview process that appear to be impacting access to eye care for people of aboriginal background in Northern Alberta: economic factors, societal and cultural barriers and the absence of cultural rituals and ceremonies.

Economic Factors

Economic and geographic considerations that play critical roles in determining access were highlighted in interviews with patients and Aboriginal Community leaders. For example, most people included in this analysis were quoted as living more than three hours away from the nearest medical facility and were dependent on their cultural healer for primary care because of this. Many considered travel itself a financial barrier. A patient said "I don't have a car, so I rely on a bus or taxi that is shared with community members. But all the time spent travel-

ling results in a loss of my wages, so sometimes it's easier not to see the doctor in the city."

Societal and cultural barriers

Interviews with community leaders, patients and nurses confirmed the magnitude of the social and cultural barriers. According to the program administrator, "prior to 2009, patients had indicated to our support staff that they were distrusting of the hospital." The Cultural Liaison said patients avoided hospitals due to their perceptions that government institutions were disrespectful since "they [government] had taken Aboriginals' land". Many felt mistreated in this setting on account of their backgrounds. The nurse from the hospital-based ophthalmology clinic said "on several occasions, Aboriginal patients became upset when other patients were seemingly assessed by a doctor before they were, although those patients were seeing a different doctor altogether." Patients told the research team they felt "uncomfortable here [hospital] because they preferred wearing casual/ragged clothing, as they did within their home communities. The hospital staff did not understand this, and sometimes mistakenly asked patients if they were 'homeless'. On one instance, this occurred with one of the most respected Elders from the community, who angrily left the hospital after the incident. Interview with a cultural liaison revealed that hospitals were also avoided due to the belief that "when in hospital, one is disconnected from Mother Earth". A common belief in some Aboriginal communities is that in order to feed the spirit, one must stay connected to nature.

There were also significant language barriers identified. One patient complained that she "didn't understand her physician and was too intimidated to ask him to slow down when conversing"; hence, she did not understand what it meant to be 'diabetic' and was unaware of the recommended changes to her lifestyle.

Absence of cultural rituals and ceremonies

The importance of cultural rituals and ceremonies within the home community was a recurring theme of the interviews. The nurse administrators explained that "appointments were almost unanimously missed if conflicting with the time of a pow-wow or other major cultural activity". Also, during the actual clinic, incorporating some element of cultural activity, such as a "Smudge" is helpful. One patient said "the Smudge is part of our traditional healing methods and it helps us to openly discuss our health, and participate with each other." In a conversation with a Cultural Liaison, it was highlighted that Aboriginal health has four main components that need to be maintained

in balance: physical, mental, emotional and spiritual. When a patient is diagnosed with a severe ocular disorder, their emotional health suffers and they are no longer in balance. The "Smudge" is a traditional medicinal purification ritual, and the burning of a plant, which can be sweetgrass, sage, fungus, roots, etc. depending on the community, attempts to recover that balance.

Patients admitted they were more trusting of nurses of Aboriginal descent and would therefore be more likely to follow their advice, such as diet-adjusting strategies. "These nurses can better understand my life on the reserve and how difficult it is to buy fruits and vegetables". In addition nurses who spoke Cree could more easily communicate with patients in their native tongue. Discussion with both the program administrator and patients reinforced the concept that community-based clinics foster feelings of trust and support amongst attendees. One patient said "when I was diagnosed with diabetes, I was depressed. But coming to this health clinic made me feel better and I wanted to start living healthier because I had the support of my brothers and sisters". Nurses believed "attendance to the clinics increased largely due to familiarity, comfort, more time spent with a patient and better understanding." The Cultural Liaison indicated that when a patient receives a diagnosis, they are not concerned with symptoms or long-term consequences. Rather, they think about how does the diagnosis affects their whole body, and their general health in terms of the 4 main aforementioned components. When the nurses speak with the patients, they would commonly ask "How do you feel emotionally? How do you feel spiritually?" This is a method of communicating about health that the Aboriginal people better understand.

In our discussions with the cultural liaison, Aboriginal people explained that they believe that "when vision is lost, it is also a spiritual loss, because when one can no longer see the sun, the animals, and the trees, one gets disconnected from Mother Earth's elements." Patients felt nurses of Aboriginal descent could better empathize about this than doctors could, and thereby provide culturally-relevant recommendations, for example citing ways to overcome this spiritual loss and better connect with nature.

Discussion

This qualitative analysis revealed four main types of barriers to healthcare access for Aboriginal communities: economic, geographic, social and cultural. Although the economic and geographic factors have been well reported previously, this study is novel in demonstrating the benefit of adding a socio-culturally-sensitive component to delivery of remote eye care. The atten-

dance rate at appointments increased from 20% to 85% within two years of adding this socio-cultural aspect.

Tele-ophthalmology helps to overcome financial and geographic barriers for patients, as they only travel to the urban tertiary care center if treatment is needed. Our interviews with patients confirmed that our program was successful at overcoming both of these barriers. Although there are start-up costs for purchasing equipment, tele-ophthalmology has been shown to save costs to the healthcare system and patients in the long-term, and is therefore a more financially sustainable alternative than hospital-based screening for many remote lower-resource settings [14-16].

The discussion with interviewees revealed socio-cultural barriers to accessing hospital-based clinics related to perceptions of discrimination, their traditional values, and communication difficulties. In a previous study on health delivery, Aboriginals identified the following negative aspects of healthcare: poor access to culturally appropriate health services, dislocation from cultural support systems, exposure to racism, poor communication with health care professionals and economic hardship [17]. Other published evidence supports our findings that Aboriginal people have a perception of discrimination and racism in the hospital, and this has been cited as a reason for lack of utilization for mental health services [18].

It is more feasible to create a specialized and welcoming program in a community-based clinic setting than in a traditional urban hospital due to regulations and the variety of populations that must be catered to; for example, the teepee and Smudge used in some ceremonies would be difficult or impossible to accommodate in urban hospitals. Also, hiring all Aboriginal nurses is much easier at a remote tele-ophthalmology clinic than would be in an urban clinical setting. Indeed, literature has illustrated that healthcare delivery is optimized when coupled with the inclusion of culturally sensitive material and communication in their native tongue [19]. The recommendations of Shahid *et al* for including culturally sensitive and empathetic personal contact and employing more Aboriginal health workers in hospitals is supported by our research. One study showed that Aboriginals drew strength from being part of an Aboriginal community, having regular and ongoing access to primary health care and being well-connected to a supportive family network [17].

In Durkin's review paper of the most sustainable and culturally appropriate ways to implement eye health programs in Aboriginal communities, it was stressed that initiatives like retinal photography services should still consider the underlying social issues that underpin the high prevalence of diabetes in several Aboriginal communities [20]. It was also emphasized

that expanding health services should not be at the expense of education and building the capacity of the people to know why and when to follow up for various conditions. We strongly agree with these concepts and suggest that this is most easily accomplished with nurses from the local community who speak Cree. Hoff describes how traditional healers may be either cultural barriers to care or facilitators [21]. They must be recognized and valued as the essential parts of the healthcare team that they are, or else they can potentially work against projects. We are supportive of these findings, and learned many lessons from the Cultural Liaisons of the Aboriginal communities. Consultation with a spiritual leader or traditional healer can improve the design of healthcare interventions targeting Aboriginals.

Tele-ophthalmology is an innovative model of health delivery that overcomes barriers to healthcare. It is inherent in its design, and well described in the literature that tele-ophthalmology overcomes economic and geographic barriers. Our research team has witnessed firsthand how tele-ophthalmology is more effective than the traditional hospital-based approaches at resolving social and cultural barriers, thereby facilitating greater access to care for remote Aboriginal communities.

Acknowledgments

We would like to thank Abshir Moalin, the program administrator who facilitated the interviews. We would also like to thank the select patients, nurses and Cultural Liaisons who participated in the study for their time and expertise. In particular, Wayne Burstick, who serves as a hospital-based Cultural Liaison, was extremely helpful in explaining Aboriginal customs and beliefs and how to choose the best terminology for describing them. Participants to the ADWP clinic all consented to the research conducted and the intention to publish the findings as a means of continuing education.

References

1. McBain-Rigg KE, Veitch C. Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa. *The Australian journal of rural health*. Apr 2011;19(2):70-74.
2. Hayman N. Strategies to improve indigenous access for urban and regional populations to health services. *Heart, lung & circulation*. May-Jun 2010;19(5-6):367-371.
3. Gionet L. First Nations people: Selected findings of the 2006 Census. *Component of Statistics Canada Catalogue no. 11-008-X*. 2009; Canadian Social Trends.
4. Frohlich KL, Ross N, Richmond C. Health disparities in Canada today: some evidence and a theoretical framework.

- Health policy (Amsterdam, Netherlands)*. Dec 2006;79(2-3):132-143.
5. Willows N, Veugelers P, Raine K, Kuhle S. Associations between household food insecurity and health outcomes in the Aboriginal population (excluding reserves). *Health reports / Statistics Canada, Canadian Centre for Health Information = Rapports sur la sante / Statistique Canada, Centre canadien d'information sur la sante*. Jun 2011;22(2):15-20.
 6. Anderson H, Kowal E. Culture, history, and health in an Australian aboriginal community: the case of utopia. *Medical anthropology*. 2012;31(5):438-457.
 7. Burnier MN, Jr. Telemedicine and tele-ophthalmology. *Canadian journal of ophthalmology. Journal canadien d'ophtalmologie*. Aug 2003;38(5):343, 345.
 8. Tennant MT, Greve MD, Rudnisky CJ, Hillson TR, Hinz BJ. Identification of diabetic retinopathy by stereoscopic digital imaging via teleophthalmology: a comparison to slide film. *Canadian journal of ophthalmology. Journal canadien d'ophtalmologie*. Jun 2001;36(4):187-196.
 9. Tennant MT, Rudnisky CJ, Hinz BJ, MacDonald IM, Greve MD. Tele-ophthalmology via stereoscopic digital imaging: a pilot project. *Diabetes technology & therapeutics*. Winter 2000;2(4):583-587.
 10. Liesenfeld B, Kohner E, Pichlmeier W, et al. A telemedical approach to the screening of diabetic retinopathy: digital fundus photography. *Diabetes care*. Mar 2000;23(3):345-348.
 11. Rudnisky CJ, Hinz BJ, Tennant MT, de Leon AR, Greve MD. High-resolution stereoscopic digital fundus photography versus contact lens biomicroscopy for the detection of clinically significant macular edema. *Ophthalmology*. Feb 2002;109(2):267-274.
 12. Rudnisky CJ, Tennant MT, Weis E, Ting A, Hinz BJ, Greve MD. Web-based grading of compressed stereoscopic digital photography versus standard slide film photography for the diagnosis of diabetic retinopathy. *Ophthalmology*. Sep 2007;114(9):1748-1754.
 13. Berry SL, Crowe TP, Deane FP. Preliminary development and content validity of a measure of Australian Aboriginal cultural engagement. *Ethnicity & health*. 2012;17(3):325-336.
 14. Au A, Gupta O. The economics of telemedicine for vitreoretinal diseases. *Current opinion in ophthalmology*. May 2011;22(3):194-198.
 15. Jones S, Edwards RT. Diabetic retinopathy screening: a systematic review of the economic evidence. *Diabetic medicine : a journal of the British Diabetic Association*. Mar 2010;27(3):249-256.
 16. Lamminen J, Forsvik H, Vopio V, Ruohonen K. Teleconsultation: changes in technology and costs over a 12-year period. *Journal of telemedicine and telecare*. 2011;17(8):412-416.
 17. Aspin C, Brown N, Jowsey T, Yen L, Leeder S. Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study. *BMC health services research*. 2012;12:143.
 18. Isaacs AN, Pyett P, Oakley-Browne MA, Gruis H, Waples-Crowe P. Barriers and facilitators to the utilization of adult mental health services by Australia's Indigenous people: seeking a way forward. *International journal of mental health nursing*. Apr 2010;19(2):75-82.
 19. Shahid S, Finn LD, Thompson SC. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *The Medical journal of Australia*. May 18 2009;190(10):574-579.
 20. Durkin SR. Eye health programs within remote Aboriginal communities in Australia: a review of the literature. *Australian health review : a publication of the Australian Hospital Association*. Nov 2008;32(4):664-676.
 21. Hoff W. Traditional healers and community health. *World health forum*. 1992;13(2-3):182-187.