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Wellness-Based Indigenous Health Research and
Promising Practices



IJH

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Health through wellness

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Welcome from the First Nations Health Authority

Welcome to the International Journal of Indigenous Health (IJIH) and First Nations Health Authority's (FNHA) co-produced special thematic issue on Wellness-Based Indigenous Health Research and Promising Practices. The FNHA is pleased to participate in this collaborative opportunity to invite, publish and share community-based and academic research articles about First Nations and Indigenous community health and wellness.

The FNHA is part of a unique First Nations health governance structure in British Columbia. One which includes political and technical First Nations health leadership, collectively striving for better health and wellness outcomes for First Nations and Aboriginal peoples in the province¹. As an organization striving for excellence through our commitment to learn continuously, we value the power of evidence to support program and system improvements. Journals such as IJIH inform our transformative work.

This special edition of the IJIH centres on research and promising practices that embed culture into health practice, including traditional feasting, intergenerational relationships, and relationships with the land. As a health and wellness organization operating within a shared First Nations perspective on health and wellness², FNHA supports shifting the conversation to more strengths-based and holistic understandings of wellness. Health research and reporting from a conventional western perspective, has historically been disease-focused and deficit-based. FNHA has heard from communities about the need for research and services positioned in *wellness*, developed by First Nations, and reflecting strengths, cultures, and self-determined measurements. Wellness-based promising practices support this vision by giving First Nations control over decisions about what constitutes evidence of wellness. Such research aligns with a First Nations perspective on health and wellness² and our work to enhance cultural safety in the health system throughout the province.

Readers will also enjoy the community-based research projects showcased in this edition, which engage Indigenous communities through diverse methods including photovoice, digital storytelling, and sharing circles. The FNHA is committed to creating the space for First Nations and Indigenous communities to self-determine their path towards wellness, Nation rebuilding and revitalizing traditional ways of life. Guided by our Seven Directives³, Shared Values⁴ and Operating Principles⁵, the promotion of community-driven research, which respects Indigenous ownership and control over the entirety of the research process, is part of transforming research ethics, data governance, evaluation, and knowledge exchange, to be more responsive and accountable to First Nations peoples.

This partnership with IJIH has aimed to promote, encourage and support research grounded in wellness and Indigenous methodologies and ways of knowing. Empowering community-based research grounded in Indigenous knowledge systems, is driving the creation of a new culturally relevant body of evidence. This first-of-its-kind edition contributes to our knowledge of how a

¹ <http://www.fnha.ca/about/governance-and-accountability>

² <http://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/first-nations-perspective-on-wellness>

³ <http://www.fnha.ca/about/fnha-overview/directives>

⁴ <http://www.fnha.ca/about/fnha-overview/vision-mission-and-values>

⁵ <http://www.fnha.ca/about>

Introduction

holistic and strengths-based understanding of wellness can be realized in academic, community-based research, and Indigenous health practice settings.

We are honoured to work with the IJIH to share this knowledge with local, regional, national and international First Nations and Indigenous communities, as well as health service and academic audiences. This work advances the FNHA's shared vision of healthy, self-determining and vibrant BC First Nations children, families and communities⁴. We hope the great work found within this edition supports an evidence-base to inform policy and service improvements among First Nations and Indigenous health systems here in BC and around the world.

In Wellness,

A handwritten signature in black ink, appearing to read 'jse', written in a cursive style.

Joe Gallagher
Chief Executive Officer
First Nations Health Authority

Wellness-Based Indigenous Health Research and Promising Practices

On behalf of the IJIH and FNHA Editorial team members, IJIH Editorial Advisory Board, peer reviewers, and authors, we are pleased to present this collection of papers on research and promising practices in Indigenous wellness-based health. IJIH utilizes the term ‘promising practices’ as inclusive of community, cultural, and regional-based health interventions that have been rigorously evaluated through frameworks that reflect Indigenous and western standards of excellence.

This edition is unique not only as a special thematic issue, but as a partnership between IJIH and the First Nations Health Authority (FNHA). FNHA delivers services to, and in partnership with First Nations in British Columbia, in a new health governance structure established by BC First Nations leadership. IJIH wishes to express its gratitude to the people at FNHA for this opportunity to collaborate, and extends a very warm thank you for their support of this edition.

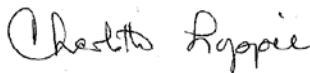
Two important parts of the academic publication process are peer review and Editorial decision-making. In this partnership, the FNHA and IJIH engaged in a collaborative editorial review process to identify papers that would be peer reviewed. This labour intensive process engaged Co-Editors and staff from both organizations. As a model for future editorial partnerships, this process provided an opportunity for both organizations to engage with and learn from one another about their respective mandates and approaches to assessing knowledge about Indigenous health. Editorial team contributions are significant and valued; individuals from both organizations worked together for many hours over the fall and winter of 2015/2016. In particular the dedication of Editorial Assistant Natasha Donovan deserves special mention.

The 2015 IJIH Call for Papers invited community-, student- and university-based authors to submit work that focused on Indigenous community- and cultural-based wellness. This reflects a dramatic shift away from potentially stigmatizing research that documents Indigenous and Aboriginal health deficits and disparities, often in isolation of cultural, social, political and economic contexts. Fortunately, current trends reflect the value of Indigenous community-based research that is grounded in traditional knowledge, holistic paradigms, and an emphasis on health and wellness across the life stages.

This extensive edition of fifteen exceptional papers, presents research and promising practices in the areas of community-based traditional healing and knowledge sharing, the role of Elders in wellness and learning, Indigenous youth leadership, and youth mental health interventions. Jen Bagelman and colleagues examine and share promising practices emerging from a community-based feast project, Coast Salish territory on Vancouver Island, Canada. Lisa Bourque Bearskin and colleagues explore how Indigenous nurses integrate traditional knowledge into their practice as part of an effort to reduce health disparities in their communities. Melany Cueva and colleagues examine the potential of digital storytelling as a health messaging tool through a five-day cancer education and storytelling course for Indigenous Community Health Practitioners in Alaska, USA. Verna Fruch and colleagues conduct participatory action research to facilitate the development and implementation of a community-based palliative care program in Six Nations of the Grand River Territory. Chelsea Gabel and colleagues conduct a community-based participatory research project using photovoice to examine the effects of intergenerational

relationships on health and wellness in one southern Labrador Inuit community. Gwen Healey and colleagues develop a model for youth mental health interventions based on Inuit philosophy and test its application through a camp program in five communities in Nunavut, Canada. Teresa Howell and colleagues examine the role that traditional healing methods play in improving health outcomes in urban Aboriginal communities through a series of health-focused talking circles in Vancouver, Canada. Renée Monchalín and colleagues conduct a thematic analysis of interviews with Indigenous youth leaders to better understand how the concept of leadership is understood within the context of HIV prevention. Renée Monchalín and other colleagues introduce a peer-led pilot health intervention that delivered sexual health promotion and education to Indigenous youth at a pow-wow. Pammla Petrucka and colleagues partner with Elder-youth teams to develop and deliver a healing initiative to students in a Standing Buffalo First Nation elementary school. Sloane Real Bird and colleagues explore a Crow community's perceptions of the link between loss and chronic illness in order to facilitate more effective chronic illness management. Keren Tang and colleagues work with Dene youth to explore culturally-based definitions of physical health through a participatory video project and community discussions. Joshua Tobias and Chantelle Richmond use locally-relevant forms of knowledge translation to discuss strategies for environmental repossession with Elders in two Anishinaabe communities in Ontario, Canada. Alasdair Vance and colleagues propose a framework to promote wellness among Aboriginal patients in urban Australian hospitals that embeds culture into assessment, formulation and treatment. Janice Victor and colleagues work with youth in a Nehiyawin First Nation to co-research wellbeing and encourage the development of self-knowledge and cultural identity using participatory arts methods.

We invite you to enjoy, learn from and share the stories, experiences and lessons shared in this very special thematic issue produced in collaboration, partnership and friendship.



Charlotte Loppie
Editor, IJIH



Amanda Ward
Co-Editor, Special Thematic Issue



Namaste Marsden
Managing Editor

The International Journal of Indigenous Health (IJIH) is honoured to provide a space for innovative, high quality, Indigenous community-grounded, student and university-based research. This Journal fills a gap in the current landscape of Canadian and international health and research Journals. IJIH is firmly committed to engaging members of Indigenous or Aboriginal communities in creating and determining, via peer review, what is included in this growing body of literature. IJIH (formerly the NAHO Journal of Aboriginal Health) has engaged community-based and university based Indigenous health scholars and practitioners in its unique dual, double-blind peer review process for twelve years. This process ensures a high degree of quality and community relevancy in papers published by the Journal and helps to shape the standards for content, process and interpretation of Indigenous health research.

The IJIH is online, open-access and free. You can support the IJIH by making a donation, signing up to receive updates on the IJIH website, and volunteering as a peer reviewer.

Feasting for Change: Reconnecting with Food, Place & Culture

Abstract

This paper examines and shares the promising practices in promoting health and well-being that emerged from an innovative project, entitled “Feasting for Change”. Taking place on Coast Salish territories, British Columbia, Canada, Feasting for Change aimed to empower Indigenous communities in revitalizing traditional knowledge about the healing power of foods. This paper contributes to a growing body of literature that illuminates how solidarities between Indigenous and non-Indigenous communities can be fostered to support meaningful decolonization of mainstream health practices and discourses. In particular, it provides a hopeful model for how community-based projects can take inspiration and continual leadership from Indigenous Peoples. This paper offers experiential and holistic methods that enhance the capacity for intergenerational, land-based, and hands-on learning about the value of traditional food and cultural practices. It also demonstrates how resources (digital stories, plant knowledge cards, celebration cookbooks, and language videos) can be successfully developed with and used by community to ensure the ongoing process of healthful revitalization.

Keywords

Food, medicine, experiential learning, intergenerational, health, wellness, resilience, revitalization, feasting

Authors

The research, analysis, writing, and revisions of this paper were shared between the three authors:

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Fiona Devereaux is an Aboriginal health dietitian for the Aboriginal Health Program, Island Health, Victoria, BC. She has worked closely with Aboriginal communities for over 14 years. As part of a larger working group, Fiona worked alongside Aboriginal communities, facilitating the implementation of Feasting for Change.

Raven Hartley is from the Rainy River First Nation, ON, Canada, and played a key role in Feasting for Change as an activity coordinator and youth advisor.

Acknowledgements

We extend gratitude to the following people who provided heartfelt vision, energy, and support throughout Feasting for Change: numerous Elders and Knowledge Keepers who shared and supported all 51 feasts; Earl Claxton Jr., Anna Spahan, Isabelle Charles, John Bradley Williams, Sandy George, Jen McMullen, Kate Kittredge, Camielle Henry, Nancy Turner, Judith Arney, T'Sou-ke Nation and Administration, Pakki and Henry Chipps, Erin Rowsell, Sue Schaefer, Cheryl Bryce, Joan Morris, Belinda Claxton, Stewart Anderson, Danella Parks, Vancity, Tracy Cullen Horner Foundation, BC Healthy Living Alliance, Jessica Chenery, all South Island Nation chiefs and councils and health leadership, Snaw-naw-as First Nation, Namgis First Nation, and so many more.

Introduction

To take the territorial lands away from a people whose very spirit is so intrinsically connected to Mother Earth was to actually dispossess them of their very soul and being; it was to destroy whole Indigenous nations. Weakened by disease and separated from their traditional foods and medicines, First Nations Peoples had no defence against further government encroachments on their lives. (Fred Kelly, Anishinaabe Elder, Truth and Reconciliation Commission of Canada, 2015).

We commence this paper with the poignant words shared by Anishinaabe Elder and residential school survivor Fred Kelly in his testimony to the Truth and Reconciliation Commission of Canada (TRC, 2015). These words are part of a living archive that speaks to the grave violence inflicted upon generations of Indigenous people across this country. As this opening quote reveals, one of the damaging impacts of Canada's colonial policies and practices is that they aim to disconnect Indigenous Peoples from their land, their foods, and their medicines, which feed not only the body, but the heart and spirit.

The TRC reported that within Canada's residential schools, food policies played a particularly violent role. In fact, this process of culinary acculturation was a key feature of colonialism (Turner, 2014). In addition to being separated from their families and their land, children were denied access to their traditional diets. In their home communities, many students were raised on food that their parents hunted, fished, or harvested. These meals were very different from the European diets served at the schools. Porridge every day, hardtack biscuits, and powdered milk; these were some of the foods that were served in residential schools, replacing rich traditional diets. As indicated in the TRC (2015) this "change in diet added to the students' sense of disorientation" (p. 91). As well as being denied traditional foods, in many cases children were denied food to the point of severe malnutrition and starvation. Indeed, the TRC affirms that thousands of Indigenous children died of malnutrition as a result of such colonial policies.

While Canada's last residential school closed in 1996, it has been widely acknowledged that the legacy of these schools has had lasting traumatic impacts. The colonial food practices

enforced in residential schools did not end when the doors of the last residential school were shut. In part as a result of being disconnected from traditional foods and subjected to severe malnutrition, Indigenous people continue to face disproportionately high rates of dietary illnesses such as Type 2 diabetes and heart disease (Turner, 2007). For instance, Indigenous people aged 45 and older have nearly twice the rate of diabetes as the non-Indigenous population. As the TRC and various scholars have asserted, closing the gap in these health inequities must remain a priority if reconciliation is to be achieved (Bisset, Cargo, Delormier, Macaulay, & Potvin, 2004). A key question that emerges from the TRC is: How can health agencies in Canada support Indigenous communities in reconnecting with and revitalizing traditional food systems that hold the possibility for healing?

In keeping with the teachings shared by Cheryl Bryce of the Lekwungen, we believe that this type of revitalization starts with “protecting the land, reinstating traditional roles, and practicing everyday acts of resurgence” (Corntassel & Bryce, 2012, p. 158). This paper explores how a project entitled “Feasting for Change” has modestly contributed to this ongoing process of healing. Feasting for Change took place on Coast Salish territories and was inspired by the knowledge of traditional food practices among Indigenous Peoples of this land.

Drawing on Indigenous research methodologies, this paper is written in a conversational, storytelling format and attempts to privilege the voices of communities who participated in Feasting for Change. As some Indigenous scholars have suggested, it is vital that we expand academic spaces to include modes of knowledge exchange, such as story, that continue to play a vital role in many Indigenous communities (Kovach, 2009; Kulnieks, Longboat, & Young, 2010). Embedded in this narrative are photographs taken during Feasting for Change events so as to situate this project within its Coast Salish context.

Methods

Setting the Table

On a foggy day in late May 2007 invitations were delivered to Elders across south Vancouver Island. They were invited to a feast, prepared and hosted by the T'Sou-ke First Nation in collaboration with Island Health, Lifecycles, and Vancity. As the smell of freshly steamed halibut and crab lifted in the air, guests came together around a large table to share foods prepared in time-honoured ways. Over this feast, people shared stories about both the loss of their food and the value of revitalizing their food practices (Figure 1).



Figure 1. Feast prepared and hosted by T’Sou-ke First Nation, 2007.

This 1-day event hosted by T’Sou-ke First Nation was also supported by Aboriginal health dietitian Fiona Devereaux, from Island Health, in an effort to nourish a space for dialogue about food and its role in community. During this feast, it became apparent that there was an appetite to host future events like this one. In particular, participating communities articulated a keen desire to promote feasting as a platform for Elders to share their knowledge with youth and their community.

Given the vibrant support articulated by Elders and the wider communities at this initial event, a collaborative project called “Feasting for Change” was envisioned. Feasting for Change, it was collectively imagined, would create opportunities for First Nations across Vancouver Island to continue to host feasts and engage with people about the food and nutrition needs in their community.

A key question emerged in the early planning of this project: How exactly do Island Health and others play a “supportive” role in this process? The goal of the project was, after all, to create opportunities for Indigenous people to reconnect with and revitalize their *own* knowledge. Given the deep colonial legacies of health services in Canada that position Indigenous people as recipients and settler health practitioners as providers (Kelm, 1998), what place, if any, should Island Health have in this project? Indeed, this question connects to broader issues raised by Indigenous scholars, such as Glen Coulthard (2014), who asks: How might non-Indigenous allies work in solidarity with Indigenous struggles for decolonization and self-determination?

A series of conversations between Indigenous communities and Fiona Devereaux took place in order to identify how—or indeed whether—to move forward with this as a joint project. It was determined that a “solidaristic” (i.e., undertaken in unity) project could be possible if all events associated with Feasting for Change took leadership from First Nations. In particular, it was determined that Elders would play a leadership role, identifying proper protocol for all activities. Respected Tsawout Elders, such as Earl Claxton Jr., had a strong leadership role

throughout the duration of the project. Additionally, it was determined that youth should play a role in facilitating and guiding the overall project. Raven Hartley played a significant role as youth advisor, and her gentle community-building energy provided meaningful direction for Feasting for Change.

Based on community consultation, a diverse working group grounded in the protocol of local First Nations was also formed. The working group comprised Indigenous communities, Island Health, community groups, individuals, and students from the University of Victoria. The structure of this group was based on the principle of reciprocity and was aimed at creating a caring environment where ideas could be freely shared. As testament to the success of this vision, Raven Hartley stated at the end of the project: “Although we might call this a ‘working group,’ it is really more the Feasting for Change family.” It was collectively determined that the working group’s role would be to “set the table” and let the community create their feasting vision. Part of this role would also involve the working group securing funding to allow these feasts, and associated events, to become possible.

As an active member of the working group, Fiona Devereaux reflected on this method of engagement:

There is so much knowledge and story in the communities. Many people just need a venue to share this with their community. And the youth are just as excited to learn how to pick berries, harvest seafood, build a pit, barbecue salmon, and celebrate their families, culture, and foods.

Really it is about “setting the table” and letting the magic of community happen (Figures 2 and 3). The role of the working group, in other words, is not to impart knowledge about food or healthy eating but to create space—set the table—for meaningful exchange, engagement, and experiential learning within and between Indigenous communities to revitalize their own knowledge systems. In order to share the findings of this process more widely, Feasting for Change also collaborated with a community-engaged researcher based at the University of Victoria (Jennifer Bagelman) to facilitate the documenting of this project. The method underlying Feasting for Change is thus one defined by an intercultural, interdisciplinary collaboration that brings together Indigenous Peoples, community organizations, Indigenous health agencies, and the university. This relationship is rooted in First Nations protocol.



Figure 2. Feast in Pauquachin, 2010.



Figure 3. Feast in Malahat, 2007.

Results and Discussion

From 2007 to 2012, Feasting for Change led 51 feasts and 10 other events inspired by the diversity and wisdom of the Knowledge Keepers and Elders in the nine South Island Coast Salish communities and a large urban community served by the Victoria Native Friendship Centre. These events reached over 5,000 people. First Nations communities primarily across southern Vancouver Island revived their traditional food practices through a host of activities, which included traditional salmon barbecue, pit cooking, berry picking, cleaning fish and crab, plant walks, and making tea.

During one such event in August 2011, Elder Earl Claxton Jr., J. B. Williams, and Fiona Devereaux collaborated with leaders in the community to host a workshop in Pacheedaht on how to traditionally can salmon, smoke clams on oceanspray sticks (ironwood), and make scow bread with fresh blackberries. During another event on a beautiful day later in August, the SCIA'NEW First Nation prepared a feast for 60 people to experience a traditional pit cook, and shared their method and technique along the way (Figure 4).



Figure 4. SCIA'NEW First Nation leads a pit cook, 2007

Meanwhile, as food steamed in the pit, a group of children were led by a Knowledge Keeper, Pakki Chippis, on a nature walk to view and learn about the “vast plant people” that grow and thrive in their community. In July 2007 the Pauquachin First Nation hosted a 2-day

community event that included a plant and berry gathering day and a huge feast. People ages one through 90 shared stories, skills and delighted in baked fish, clam chowder, fresh berry crumble, as well as traditional tea made by a local Elder, Elmer Henry. The Pauquachin feast sparked energy within the community to serve more traditional foods at their weekly community lunches, and to start a community fish cleaning and canning day. As Feasting for Change was gaining momentum, across the island other key food programs were emerging. For instance, Tsawout First Nation hosted its first Seafood Festival, attracting 800 people. Uu-a-thluk Fisheries was creating its community capacities program that hosted community food events. In addition, the first Traditional Foods Gathering took place in Nanaimo. Throughout this gathering, the Vancouver Island and Coastal Communities Indigenous Food Network (VCCIFN) was established. A revitalizing of Indigenous food, land, and culture was palpable.

Based on verbal feedback gleaned from the 51 hosted events, three key experiences were expressed as meaningful impacts of this project: revitalizing, intergenerational exchange, and community building. The testimonies below were shared by participants and speak to these outcomes.

Revitalizing

Many community members reflected on how Feasting for Change allowed them to reconnect with traditional foods (Figure 5), and the emotional and physical impact this had:

This is the first time I have tried these foods or seen food cooked in the ground.

I feel proud about how the old people used to do things.

I miss these foods; it is so nice to have them; my body always feels better when I eat them.



Figure 5. Lenore Jones enjoys barbecued clams in Pacheedaht First Nation, 2011.

Intergenerational Knowledge Transfer and Education

Many community members identified that one of the measures of success of this project was that youth reflected on a deepened sense of traditional knowledge after events (Figure 6). Participant Sandy George of Songhees First Nation stated:

I know my dad and family know a lot about food, but they don't do it anymore. Spending time at these feasts and seeing the vast knowledge and skills around food has inspired me to go home and ask more questions and see if my family will teach me.



Figure 6. Earl Claxton Jr. sharing how to clean crab at Pauquachin feast, 2009.

Community and Relationship Building

Reflecting on the community-building role played by Feasting for Change (Figure 7), First Nations community members shared the following statements:

It was so nice to have the families and friends together and having good times around our food.

People don't really get together a lot anymore as a community, but everyone was together that day. We usually only see each other at funerals.

I have never seen Indigenous people showcased in such a loving and family-focused way. The media never does that.



Figure 7. Elmer Henry teaches Sue Schaefer (diabetes nurse) how to cut fish, 2007.

In addition to the events themselves, which helped reconnect people with traditional foods, promoted intergenerational exchange, and stimulated community building, Feasting for Change also produced three sustainable resources: (a) a celebration cookbook; (b) digital stories, including SENĆOŦEN food and language videos; and (c) plant knowledge cards.

Feasting for Change Cookbook

“This book shares stories, teachings and tips on eating food through the seasons. Through Spring, Summer, Winter and Fall this book provides an opportunity to learn more about salmon, plants, teas, clams, mussels, gooseneck barnacles, BBQ fish, bread and more!” These words are written on the back cover of the *Feasting for Change* cookbook (front cover shown in Figure 8).



Figure 8. *Feasting for Change* cookbook, published in 2011

This book celebrates some of the Indigenous foods of Vancouver Island. Created through the teachings and learnings from Feasting for Change’s many events, and inspired by the diverse

wisdom of Elders and Knowledge Keepers, it provides a tangible resource for community to engage with these teachings in an ongoing way.

Digital Stories and SENĆOŦEN Food and Language Videos

Many First Nations communities have identified that promoting a healthful reconnection to Indigenous food systems simultaneously requires revitalizing Indigenous languages (Corntassel & Bryce, 2012). As Cheryl Bryce has suggested, a healthy and diverse diet that is connected to language revitalization enhances environmental sustainability as well as emotional, spiritual, and physical health (Corntassel & Bryce, 2012). Recognizing this holistic revitalization process, Feasting for Change placed a strong emphasis on supporting knowledge about food in traditional language throughout all events and in all resources produced. As part of this vision, Feasting for Change partnered with Saanich Adult Education Centre and the SENĆOŦEN apprentices to create five videos in SENĆOŦEN language about local food and plant knowledge. These videos were shared during feasts, not only promoting connection to traditional modes of preparing and eating food but also enhancing the languages used to convey meaning about these culturally significant foods and rituals.

Feasting for Change Plant Knowledge Cards

Inspired by over 100 plant walks and talks, which were led by Elders and Knowledge Keepers in the forests of Pacheedaht, the tide pools of Tsawout, and other locations in southern Vancouver Island, Feasting for Change created a set of 66 different cards identifying edible and medicinal plants native to this region.

Beautiful photographs of the plants by John Williams and Nancy Turner capture the eye and stir a sense of place. In keeping with the effort to revitalize knowledge of traditional languages, accompanying these images, the names of these plants are presented in three different Indigenous languages: SENĆOŦEN, Hul'q'umi'num, and Ditidaht.

Each card describes traditional uses and ways of harvesting plants, featuring seasonal indicators and a legend to help quickly identify uses. These cards serve an educational purpose, noted Jen McMullen, who helped create the cards along with members of the working group: "It's important to recognize that these foods and medicines are still being used and we need to treat them with respect so they will still be available to our grandchildren's grandchildren."

The cards are designed to encourage engaged, experiential learning about plants in the region. The description printed on the sage-coloured card box invites people to

bring [the cards] out on walks to help identify plants, their uses and keep the old ways strong. Much of the plants and knowledge within these cards is focused on the Coast Salish Territory. Many of these plants have more uses and more stories attached to them than is featured here. Please use these cards as an inspiration to talk to an Elder or Knowledge Keeper.

Ongoing Challenges

We acknowledge that Feasting for Change is only one small part of a larger process to enhance understanding of the different uses and teachings around precious foods on Coast Salish territory. The resources produced through Feasting for Change are considered living documents that will be added to and reassessed over time. We see Feasting for Change as part of the reconciliation process identified in the TRC, as an ongoing process of decolonization that requires continued commitment.

A key question that community has identified for future work is this: How do we ensure youth can take a leadership role?¹ At present, Island Health is working with community on a follow-up project, entitled “Food Is Medicine,” that begins to explore how youth might play a leadership role in translating traditional food practices through arts-based projects. A challenge to future success of many community-based initiatives like Feasting for Change is building enough capacity to ensure ongoing momentum. In an effort to build capacity, Food Is Medicine nourishes relationships with existing Indigenous youth programs in the region. In particular, Food Is Medicine partners with the excellent community school garden and restoration project that was created by Feasting for Change, called PEPÁKEN HÁUTW (Blossoming Place), at LÁU, WELNEW Tribal School (see <http://crdcommunitygreenmap.ca/location/pepáken-háutw-blossoming-place>).

Conclusion

Exploring the design and implementation of Feasting for Change, this paper shares a variety of methods for meaningful, culturally appropriate, community-engaged health promotion. Feasting for Change illustrates how First Nations can meaningfully play a steering role with a wider working group, comprising both Indigenous people and non-Indigenous allies, in an effort to promote health and well-being and cultural revitalization. This work directly contributes to the existing literatures that dynamically explore the importance of solidaristic relationship building (Corntassel & Bryce, 2012) and the revitalization of food knowledge (Manitowabi & Shawande, 2011; Turner, 2007), which help set the table for the wider goal of reconciliation.

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¹ Identified as a key question based on feedback provided by 57 Elders at the 39th Elders Gathering held hosted by the Tsawout First Nation and WŚÁNEĆ Nations, Panorama Recreation 2015.

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Mâkawoh Kamâtowin, “Coming together to help each other in wellness”: Honouring Indigenous Nursing Knowledge

Abstract

This paper is the result of coming to know and better understand Indigenous nursing experience in First Nations, Inuit and Métis communities. Using an Indigenous research approach, I (first author) drew from the collective experience of four Indigenous nurse scholars and attended to the question of how Indigenous knowledge manifests itself in the practices of Indigenous nurses and how it can better serve individuals, families, and communities. This research framework centered on Indigenous principles, processes, and practical values as expressed in Indigenous nursing practice. The results were woven from key understandings and meanings of Indigeneity as a way of being. Central to this study was that Indigenous knowledge has always been fundamental to the ways that these Indigenous nurses have undertaken nursing practice, regardless of the systemic and historical barriers they faced in providing healthcare for Indigenous people. The results of this research demonstrated how Indigenous nurses consistently drew on their inherited Indigenous knowledge to deliver nursing care to Indigenous people. Their identity as Indigenous persons was integral to their identities as Indigenous nurses. Of significance is the personal and particular description of how these Indigenous nurse scholars developed their nursing approaches in relevance to how health and healthcare delivery must be integrated into healthcare systems as a pathway to reducing health disparities.

Keywords

Indigenous research methodologies, Indigenous nurses, Indigenous nursing knowledge, nursing practice, Indigenous wellness

Glossary

Indigenous Peoples: used in this article to mean First Nations, Inuit, and Métis peoples in Canada and used synonymously with the term Aboriginal Peoples enshrined in Section 35A in the Constitution Act of 1982. The Royal Commission on Aboriginal Peoples (1996) states that in over 605 different First Nations communities, some people prefer to identify themselves as part of their linguistic group, such as Cree, and/or Métis, or both.

mâkawoh kamâtowin: Cree term used to describe the meaning of Indigenous community development.

nohkum: Cree for “my grandmother.”

nikawy: Cree for “my mother.”

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Madeleine Kētēskwew Dion Stout, PhD, Kehewin First Nation, retired nurse, co-searcher, active educator, researcher, and author. Helped shape the study through her insights on Indigenous health and wellness; insistence on home-grown and complementary interventions and services; and insertion of Cree concepts to change the way this research project offers content.

Evelyn Voyageur, PhD, from the Dzawada’enuxw First Nation, is a retired RN and an Elder-in-residence at North Island College in Comox Valley, BC. Shared expert Indigenous nursing knowledge as a co-searcher, supported data analysis, and provided expert insight throughout the research process.

Alice Reid, retired RN, NP, worked extensively in northern Alberta. She is Métis from Sandy Lake, AB. Played a key role as a co-searcher, supported data analysis, and provided guidance throughout the research process.

Lea Bill, RN, BScN, from Pelican First Nation in Saskatchewan, is a project manager for Alberta First Nations Cancer Pathways project, president of Spirit Feather Consulting, and a traditional practitioner. Provided spiritual guidance in addition to her role as a co-researcher, supported data analysis, and acted as language interpreter throughout the research process.

Elder Rose Martial, Denesuline from Cold Lake First Nations, AB, is a retired community health representative who guided this work from its inception. She continues to work as a community researcher and as an Elder advisor to the Access Research Project at the University of Alberta with Dr. B. Cameron.

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Introduction

The aim of this research was to draw on Cree/Métis understanding through Indigenous research methodologies (IRM), in order to explore how Indigenous knowledge systems and identity are embedded in the nursing practices of four Indigenous nurse scholars. Attention is given to Cree ways of being, knowing, and acting when situated at the intersection of nursing and the hierarchy of Western nursing knowledge. As Weber-Pillwax (1999) explained, the central tenet of IRM is that the one who searches becomes the “active center” to also reveal and present his or her own story along with the emerging stories of those who are re-searching from within their own worldviews. Therefore, my¹ own life experience as an Indigenous nurse was as central to the study as were the life experiences of the other four Indigenous nurses, and all experiences were interwoven into one collective story of being Indigenous nurses in Canada. The substance of this study was grounded in the primary concern of nursing, that is the health of people, but specifically, it examined the context of delivering culturally appropriate and safe care.

Relationality

To strengthen my research approach, I drew on courses grounded in traditions of Aboriginal or Cree/Métis Peoples, offered by the University of Alberta through the Indigenous Peoples Education graduate program. For example, the Cree language graduate course² that I took with Elder John Crier and Cora Weber-Pillwax supported my own Indigenous knowledge system. In this relationship I was able to draw on traditional knowledge embedded within key words, and I began to accurately and critically examine the significance of Cree/Métis teachings in my inquiry on Indigenous nursing practice. Being attentive to the variances in meaning

¹ This paper is written from the first-person perspective of the first author.

² University of Alberta course EDPS 501: Meaning and Structure of Cree Language. Objective: With course instructor, a Cree language and traditional knowledge teacher and the students will examine the roots and structures of Cree words that carry significant and ancient values and root meanings related to Cree knowledge systems and ways of being.

between languages was important, as not all of the four Indigenous nurses were Cree/Métis; one of the nurses was from the Dzawadaǵenuǵw First Nation on the West Coast.

An important feature of this work is captured from a Northern Plains Cree/Métis perspective. *Mâmahoh kamâtowin* is a Cree term that I understand to mean “to help each other in a collective sense.” The goal of this original research was not to separate my life from my work, but rather to support and enable me to situate myself within the work as a specific and whole context where, as described by IRM, the “self” is a central aspect of the study and its incumbent relationships.

Locating Myself in the Context of the Research Inquiry

As a Cree/Métis woman who has survived life experiences rooted in violence, residential school, and the child welfare system, and who lives with the effects of intergenerational trauma,³ I continue to witness many forms of violence that First Nations, Inuit, and Métis Peoples experience. As a nurse, I have come face to face with this in my everyday life. Some of those moments are imprinted in my memory forever and have shaped my thinking on many levels. What I have come to know intimately is that nurses struggle with their personal moral convictions when they are confronted with Indigenous clients. Nurses in these situations are faced with what Cameron (2006) has referred to as the *unpresentable*: cases such as the murdered and missing Aboriginal women in Canada, and the cultural genocide that stems from effects of residential schools (Truth and Reconciliation Commission of Canada, 2015). Yet, even though this history of trauma is recognized as factual and historical in Canada, Allan and Smylie (2015) found that healthcare professionals respond to Aboriginal people by offering racialized care that renders us uncivilized, without human dignity and human rights. In some cases, even human touch is denied, as was seen in the case of Brian Sinclair, an Indigenous man who waited over 34 hours in a hospital emergency department to be assessed for a simple blocked catheter and died unattended while waiting for care (as detailed in the inquest report; Preston, 2014). Dion Stout (2012) reported that nurses are not well informed about Indigenous people’s histories, or their suffering as individuals, families, and communities living under poverties and policies that render them invisible and unpresentable.

Research Framework

As described by Ermine (1995, 2007), Kirkness (2013), Kovach (2009, 2013), Weber-Pillwax (1999, 2001, 2003, 2004, 2008), and Wilson (2008), the IRM framework draws on critical, self-reflexive, hermeneutic analysis, a process that helped me engage in a deeper self-understanding and unearthing of experiences used in the context of this study. Meyer (2008) and Ranco (2006) describe hermeneutic analysis as a way to understand the “other” and use it to enhance our own Indigenous ways of knowing. IRM is an approach that centers Indigenous

³ According to Bombay, Matheson, and Anisman (2009), *intergenerational trauma* is a term used to describe years of trauma (personal/collective) that is transmitted across generations.

identity (Weber Pillwax, 1999) and provides a research process (Kovach, 2009) and practical values (respect, responsibility, reciprocity, and relevance; Kirkness & Barnhardt, 2001). From these theoretical underpinnings, the research design captures four key components of the research process based on Cree understanding: creating respectful research activities; enacting ethical relationships; being responsible for the gathering, documenting, and analysis of data; and ensuring that mutual reciprocity is honored for the purposes of understanding the spectrum of Indigenous nursing knowledge as informed by the four Indigenous nurses, and more powerfully, by *nohkum*, *nikawy*, and myself. One of the objectives of this study was to learn and to understand what Indigenous nursing knowledge consists of and how this knowledge is infused into the practices of nursing as a means to facilitate and create healing and wellness. This objective aligns with the original research question addressing lived experiences of Indigenous nurses as practitioners and scholars.

Data Gathering

In maintaining respectful, relational, responsible, and reciprocal features of this study, the four Indigenous nurse scholars became co-researchers in the process of seeking a collective understanding of Indigenous ways of knowing and being (Meyer, 2003, 2008; Ranco, 2006; Struthers, 2001, 2003). A combination of protocols, data collection methods, and analysis techniques were used, including participant observation, self-reflexive writing, one-on-one conversations, and research circles of understanding. These activities facilitated sharing of our experiences and deepened the critical and analytical nature of our discussions, which facilitated a deepened integration of methodological features of the research phases. The Indigenous nurses became actively involved through various circles of conversation in generating, positing, sorting, questioning, understanding, and recontextualizing the data in ways that supported my constant assessment of the relationship and connections between emerging knowledge. I received their feedback and used it to extend and foster our own understanding as an effective means to “address social issues in the wider framework of self-determination, decolonization, and social justice” (Smith, 2012, p. 4).

Data Analysis

This reiterative inductive process of analysis involved a constant movement back and forth from the written text to the shared thoughts and words of the Indigenous nurse scholars. The goal of the data analysis process was to obtain a rich description that accurately depicted the statements, thoughts, and experiences of the Indigenous nurse scholars, and that was aligned with the relational commitments of our nursing work. The first analysis phase involved a line-by-line review of transcribed textual data by the researcher; the review was then mapped out and returned to the Indigenous nurse scholars. This second analysis phase involved a deep layer of thinking in which the nature of the text, both spoken and written, guided the analysis as various and distinct aspects of Cree ways of knowing and being revealed themselves to the Indigenous nurses. This allowed for the development of a collective analysis where main ideas of content

themes were generated from the renewed and/or deeper collective meaning and where the collective nature of both process and outcome simultaneously enhanced reliability and rigor of the research process. Member checking and peer debriefing were embedded naturally into the IRM processes and also provided validation of our collective interpretations and ascribed meanings to the data. Research ethics were based on IRM principles, thus going beyond the minimum standards outlined by OCAP⁴ and the Tri-Council (CIHR, NSERC, and SSHRC, 2014) for working “with, for, and by” Indigenous Peoples.

Results

The results of this original research study were interpreted and reported as deriving from two sources of knowledge: ontological beginnings and epistemological openings. Specific to each section were particular threads of understanding that resonated across the women’s lives. These threads, woven from the narratives of Indigenous nurse scholars, showed the meanings and implications of Indigenous nursing with families, communities, and Nations. Including threads of my own narrative in the results was vital to maintaining the holistic nature of this discussion of Indigenous nurses’ knowledge. There were many significant results in the original study, but for the purposes of this manuscript, I drew on a few of those threads that referred to ontological beginnings and epistemological openings as the roots of the nurses’ wellness statements.

Ontological Beginnings and Epistemological Openings

The contributions of the Indigenous nurse scholars showed that they lived according to the roots of their being and that these roots were central to their identity. They constantly reminded me that “knowing who you are and where you come from” is foundational to our existence. Alice Reid affirmed the notion of identity in all of her discussions: “We are all creatures of creation, and from that sense we are all one with unique experiences.” She spoke to these early roots of the nature of being, knowing, and doing; in other words, of the ontological and epistemological markers of her Cree/Métis worldview:

“It is always with us. It is a given, and it is up to us to accept it or not. It is not something we claim; it is just being who we are and what we believe and how we behave.”

This state of being is the personal agency within every individual. It is always in relation to our families, deeply rooted in the underground of our history and the land of our origin.

Likewise, Evelyn Voyageur spoke about her early roots of existence and the importance of her Elders’ teachings. She also talked extensively about how the notion of self is rooted in

⁴ OCAP[®]: Ownership, Control, Access, and Possession is a registered trademark of the First Nations Information Governance Centre (FNIGC; www.fnigc.ca).

community. Evelyn shared a story that captures the philosophy of community wellness as a ceremony:

The Spirit dance is bound in the teaching of protection, and it used to be done in the early morning. And it only belongs to the Willie family, my dad’s side, and my great niece holds the dance. It happens at four o’clock in the morning, and we would go to the big house. She carries a big basket to collect all the bad energy, and then she throws it in the fire. And that was how our day often began. She was also known as a healer.

This story shows the spirit of her people, their relationship to knowledge, and their understanding of how to act in accordance with traditions in the collective to preserve health and wellness. Lea Bill also described her roots as deeply embedded in her ancestors’ identity and language:

It has always been there because right from the time I was very young my grandmother taught me. She was a midwife and a medicine woman, if you might call her that; she was onanatawihowew, which translates to ‘the one who helps with healing.’ It has to do with nantawih, meaning ‘to support,’ or ‘to bring up the body,’ natawihiehiwewin. Or ‘building up the body,’ wiyaw. So it has to do with supporting the body. So right from the time I was young, I was witness to and participated in our traditional ceremonies, and I became a helper early in my life.

When she was a young girl, Lea’s connection to her grandmother set a path that she would follow for the duration of her life. Her grandmother was a midwife and traditional healer who heavily influenced Lea’s commitment to healing and encouraged her to pursue nursing in the “Western way.” Lea grew up immersed in the helping relationship through which she learned the principles of natural law.⁵ Over the years she became skilled in ways to ground her nursing care in her own traditional healing knowledge systems.

Early roots of Indigenous knowledge. From an Indigenous perspective, our traditional Cree names represent a kindred spirit and a deeper meaning. As Madeleine Dion Stout noted, our coming to know is often grounded in the names we hold that are interconnected, interdependent on nature and natural law. Having this understanding brings us closer to our own knowing and being:

I was always called kētēskwew at home. It was not just a ceremonial name. It is life lived as ceremony. And when you are given that kind of name, you always remember that you are, as in my case, an ancient woman or child with an ancient spirit.

⁵ Natural law is a philosophy of life that underpins Indigenous understanding of being human; it states that everything is connected and related, from the smallest particle in the cosmos to all living and non-living forms.

It is clear from the Indigenous nursing scholars that the roots of our upbringing (being and knowing) run deeply into the familial landscape, and thus deeply into the creation of our world. Our inherited traditional knowledge comes from the roots of our ancestries (McCallum, 2014). Their families nurtured their spirits so that their backbones became strong. They learned to share their gifts so that the far-reaching branches of knowledge could take root in the minds and hearts of others. From the blood in their veins to the inscriptions on their minds, their spiritual and traditional experiences became embedded in their being. As Couture (1991) explains, primal experience of being is the “accumulation of knowledge rooted in experience that is carried forward by oral traditions” (p. 59). He discussed this as a foundation of Indigenous existence where the inner and outer worlds meet and spiritual and physical worlds are equally real and functional. Yet it is this knowledge, that the deeper layer of consciousness is integral to wellness, that non-Indigenous people often find difficult to comprehend. Further to this, Battiste (2013) suggests that non-Indigenous people attribute this spiritual understanding to the lack of civilization amongst Indigenous Peoples. As I interpreted what the Indigenous nurse scholars said, I thought about the pedagogy of spiritual knowledge in relation to epistemological openings. *Openings* meaning those opportunities where Indigenous nurses can walk in their own way of knowing. In her research with Cree and Ojibwa healers, Struthers (2001 & 2003) recognizes that Indigenous people do not learned Indigenous knowledge from books, but from other people, and through dreams, visions, and genetic memory. The memory of the ancestors is in our blood, within our genetic makeup. This visceral level of knowledge expressed in blood memory plays a significant role in cellular development, and that cellular memory can change one’s emotional state (Pert, 1997). According to Elder Lionel Kinunwa (as cited in Steinhauer, 2002):

We have ancestral memories in our blood; they are in our muscles, they are in our bones, they are in our hair. ... These memories come out of the molecular structure of our being. ... When you hear someone speaking your language, your molecular structure picks up those vibrations, because each language has its own peculiar patterns (p. 76).

Hampton (1995) also talked about the significance of memory coming before knowledge; it is here that I see the implications of memory and knowledge of our routes and roots in life. As Battiste (2013) suggests, “Maybe this wisdom is taking its rightful place” (p. 17). When I think about memory, I think about the circularity of knowledge because if knowledge comes from the wisdom and experiences of the people, then memory takes us back to the beginning of knowledge development. Memory is central to who we are and to our outwardly lived practices; Indigenous nurse scholars pull their ancestral knowledge into their everyday lives. Their truths, origins, and memories are central to what they share and receive. The nurse scholars told me that we have no choice in the memories that we are given, but we do have a choice in the memories we accept because they deeply shape who we are today and who we are becoming.

Integrating roots of knowledge into nursing practices. What follows is a very brief but personal and particular description of how these Indigenous nurse scholars developed some of their nursing approaches based on Indigenous teachings with which they had grown up. These Indigenous nursing scholars made visible to me the roots of their individual identities, and I saw how the nurses each manifested themselves in their own distinct approaches to holistic nursing practices. Each demonstrated their personal, intellectual, spirited, and heartfelt perspectives on their own historical relationships as Indigenous people. Each created a unique learning experience in the context of this study and I came to realize that each played a significant role in translation of Indigenous knowledge.

My experiences with Alice Reid focused on the family unit with a specific emphasis on Indigenous women and girls. Evelyn Voyageur’s invitation to the village helped me to center my thinking on nursing education and the role of the community in education. The time that I spent with Madeleine Dion Stout helped me to intellectualize and concentrate on the philosophical and political aspects of Indigenous knowledge systems and maternal childcare. My final experience, with Lea Bill, led to a deeper personal understanding of Indigenous healing and self-care and its effectiveness in addressing historical trauma. Each of the Indigenous nurse scholars integrates their own knowing into nursing by relying on her understanding of Cree knowledge systems.

Alice’s life and beginnings were grounded in northern Alberta. As a nurse practitioner licensed in the United States, and as licensure was not fully recognized in Canada, she worked as a registered nurse with an expanded scope of practice. She often worked in isolation in rural and remote communities. Her responsibilities included everything from nursing administration to medical treatment, to assisting in births, wakes, and environmental emergency response situations. With very few resources, limited equipment, and reduced access to clean running water or heated buildings, she pragmatically solved issues and worked with what she had.

Witnessing the impact of Christianization and colonization on families was significant to her practice. She asserts that it is as real today as it was yesterday: “We have become unknown citizens in our own lands, and we have to just keep walking.” Alice’s statement captures the issue of ongoing colonial experience that continues to impact individual wellness and nursing practice. Alice’s Indigenous knowledge as well as her advanced nursing knowledge helped her to survive the harsh northern situation of remoteness and limited access to healthcare services. She is clear that she needed both of these knowledge bases to counteract the terror of lived residential school experience that affected the people she nursed. When she spoke about the meaning of family as if we “are one,” all related by one bond, one tribe, one Nation, one Mother Earth, this notion of oneness helped me situate the importance of human-centered practice. As Alice noted, First Nations, Inuit, and Métis women are “the invisible sinews” that bind the spirit of northern Indigenous women together as a way to strengthen community healing.

For Evelyn Voyageur the heart of community was always central to her worldview. I watched her deliver a unique educational experience to nursing and allied students where the community was the teacher. It was a profound and clear example of how a community-based

Indigenous knowledge teaching and learning approach had mutual benefits to cultural continuity and community development in nursing education. Discourses in cultural continuity and community development often focus on an analysis of deficit, which inadvertently perpetuates social disparities, stigmas, and mythical dogma of Indigenous people’s life histories and biographical accounts in Canadian literature (Valaskakis, Dion Stout, & Guimond, 2009). What Evelyn showed me was how nursing’s traditional teaching and learning approaches harmed some Indigenous nurse trainees, because traditional nursing education has not been grounded in the historical context in which Indigenous people live. In Evelyn’s work the entire community educates nurses, so education comes from a lived experience perspective. This provides a more realistic picture for nurses and student nurses about resiliency and strength among community members, often providing many examples of how power dynamics in relational nursing practice can be neutralized so that clients are driving their own healing and healthcare services delivery.

During the time I spent with Madeleine Dion Stout, it was evident that her contribution to nursing was well situated at the political level. Her knowledge extended beyond the realm of practice, drawing attention to the interlocking policies of practice and revealing how detrimental Western ways of knowing and being had been inscribed into the flesh of people she worked with. Against this political backdrop Madeleine worked tirelessly to challenge the oppression and ideological constructs that she had long ago learned to survive. Through her Cree theoretical lens, Madeleine addressed the sociocultural, historical, and contextual determinants of health. For example, in her keynote presentation *Original Instructions and the Politics of the Powerless: Nursing in First Nations* at the Philosophy in the Nurses’ World: Politics of Nursing Practice conference, sponsored by University of Alberta, she explained:

Nurses need to meet First Nations at their point of resistance and respect the fact that knowledge sharing is less a matter of seizing knowledge and cataloguing it and more about paying respect to the known, learning from the knowers, and fully participating in the knowing. The knowing of the prevailing context and conditions that shape the culture and structures we nurse in is a must.

At this point of resistance, Madeleine suggested that Indigenous nurse scholars hold their ground against these continuing forces as a way to create and preserve wellness. “We were never conquered peoples. We never gave up our identities or responsibilities to the government.” In this light, her reinforcement about understanding ethics and Indigenous human rights advanced my thinking from concealment of Indigenous nursing knowledge to resurfacing it, so that our focus remains on the social constructs and cultural structures in Indigenous nursing knowledge and practice. In this context, social constructs such as race, gender, and religion have been used to advance various forms of knowledge, which undermines cultural structures such as protocols and processes for learning traditional knowledge.

The unique experience of working with Lea Bill took me to the most private and sacred parts of the mountains in the Kananaskis country of Alberta. There we spent time translating the

wisdom we hold, which tells us that there is a greater life force that draws us to another’s experiences. It was about a nurse’s healing journey—being able to let go of pain and hardship, recognize one’s own personal power, and incorporate spiritual energy into our nursing being. The acts of self-healing are often taken for granted in our nursing profession. Understanding natural law and relational nursing practice requires attributes that stem from resiliency and strength. It is our duty as Indigenous nurses to be of service and to be responsive to the suffering. Lea stated that we cannot forget those who come behind us:

So many of our people have bought into the idea of the script that we are incapable, and we see the evidence of this when we look at the statistics of health. But this is a multigenerational message that has been imprinted in the people, and it’s not just our people; it is continuing worldwide.

Madeleine further explains, “We’ve tried so hard to spray our Indianness away just to get by and fit in.” The idea of trying to fit and be respected as human beings during a time when families were significantly marginalized was problematic.

From my nursing education, I learned to think from binary positions—Western and Indigenous, objective and subjective, mind versus spirit, and individual over community. What I wish I had learned was to value the knowledge found in the faces, spaces, and places of Indigeneity. One knowledge system must not be valued over another. We are all part of the human race, and each of us has a unique perspective and context in which we can flourish and contribute to world health. It is this Indigenous mindfulness that brings me closer to home—to my own Cree/Métis way of learning, seeing, and knowing. Eminent scholars and traditional knowledge holders have reminded me that the ways of knowing unfolding before us are considered science (Little Bear, 2000, 2009). The traditional knowledge from these teachings is a good example of this. These teachings are sacred ways of knowing and can take a lifetime to learn. In contrast, in nursing, I was trained to think from one worldview, which left my Indigeneity in nursing unexplored and yet to be unmasked.

Discussion

A major aim of this original work has been to articulate a better understanding of how Indigenous knowledge is taken up in nursing. There are many questions left to answer, but for the purpose of this article the aim was to describe how Indigenous nursing knowledge could be of benefit and value to the discipline of nursing. The theme of wellness was central throughout the study and showed that Indigenous knowledge is inherent in Indigenous ways of being, knowing, and doing; that it can be understood as the anchor that supports the capacity of First Nations, Inuit, and Métis Peoples to lift up the work of our Indigenous nursing leaders and sustain health and wellness of Indigenous communities. In essence this inquiry is similar to the work of Gehl (2012), who wrote about the Anishinaabe concept “Debwewin Journey”—a model

of knowing that links Western ideologies of knowing from the head to learning from the heart, the holistic nature of nursing.

This study revealed many complex issues and concepts associated with Indigenous wellness in relation to the nursing profession. This area of inquiry is extremely challenging and requires meaningful and consistent engagement, participation, and leadership of Indigenous people. Indigenous people hold the experiential understandings of their knowledge systems and their ontological and epistemological roots, which guide how they interact with and within the world. Just as important, I have come to the understanding that, regardless of our individual experiences, we as Indigenous nurses inherently bring our knowledge as Indigenous persons to our nursing practice; we know that knowledge originates within our families, communities, ancestors, and the Creator—a system that has endured for thousands of years.

The Indigenous nurse scholars talked about nursing as a “pedagogy of service” in which practice is not grounded in engagement with the other. They spoke about the need to “shift the soil” and “re-turn” to the roots of nursing, which are found within the contexts of their own Indigenous community. In recognizing the attributes and efficiency of “old” knowledge, the Indigenous nurse scholars support the creation of “new” knowledge as a means of improving the understanding of nursing services in Indigenous communities in the face of ever-growing health disparities (Fridkin, 2012). The concept of Indigenous wellness is integral to the delivery of health services, as it can offer concrete approaches and benefits that far outweigh the lack of culturally responsive nursing practice that underscores racism in nursing (McGibbon, & Etowa, 2009; Vukic, Jesty, Mathews, & Etowa, 2012). The Indigenous nurse scholars support the idea of “working together” in ways that address the Truth and Reconciliation Commission of Canada’s (2015) 94 Calls to Action. In accommodating this vision as a moral imperative, we need to make space for the unique contributions of Indigenous knowledge. We must recognize that “poverty of all kinds have stolen productive capacity and independence from many Indigenous people, leaving them confused, traumatized and in poor health” (Dion Stout, 2012, p. 12). We cannot sacrifice the old for the new or the new for the old; we have to bring them into balance in the center of the collective whole, for Indigenous wellness to flourish.

Limitations

The main limitation of this study is that we cannot ever fully understand or replicate someone else’s story because the context is almost impossible to duplicate. Yet Archibald (2008), King (2003), and McLeod (2007) explain that while stories are not complete, and are limited in presenting a full understanding, they show us a path from which we can all learn. Although it is not necessarily a limitation of Indigenous research, the Indigenous nurse scholars were not all of Cree/Métis background. This is an extremely important consideration with IRM as it is important always to remember that Indigenous knowledge from one group cannot be generalized to that of all Aboriginal Peoples.

Conclusion

In conclusion, the question remains: How do we bring Indigenous knowledge into our nursing environments? This early work provides a glimpse into how these Indigenous nursing scholars integrated the roots of their being into their nursing practices to achieve wellness through their respect for, as well as engagement and relationships with the people. Here, at the intersection of ontology and epistemology, they established a foundation upon which to foster individual, family, and community wellness. A common thread in our reflexive discussions was the belief that we do not need to give up who we are in order to be able to carry out successful nursing practices and meaningful research with our communities. Rather, we must travel to the inner spaces of our deepest thoughts to engage with ancient knowledge as a way of knowing, where we can begin a new chapter, a way of being where Indigenous nurses can flourish in Indigenous nursing practice. While the research showed many features important to the delivery of nursing services to Indigenous communities, most significant was the assertion that local Indigenous people and their community knowledge systems are needed at the core of nursing. From this work our nursing team will continue to develop further research exploring Indigenous-nurse-led practice.

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Mâdawoh Kamâtowin, “Coming together to help each other in wellness”: Honouring Indigenous Nursing Knowledge • R. Lisa Bourque Bearskin, Brenda L. Cameron, Malcolm King, Cora Weber-Pillwax, Madeleine Dion Stout, Evelyn Voyageur, Alice Reid, Lea Bill, Rose Martial •
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Promoting Culturally Respectful Cancer Education Through Digital Storytelling

Abstract

Cancer is the leading cause of mortality among Alaska Native people. Over half of Alaska Native people live in rural communities where specially trained community members called Community Health Aides/Practitioners (CHA/Ps) provide health care. In response to CHA/Ps' expressed desire to learn more about cancer, four 5-day cancer education and digital storytelling courses were provided in 2014. Throughout each course, participants explored cancer information, reflected on their personal experiences, and envisioned how they might apply their knowledge within their communities. Each course participant also created a personal and authentic digital story, a methodology increasingly embraced by Indigenous communities as a way to combine storytelling traditions with modern technology to promote both individual and community health. Opportunities to learn of CHA/Ps' experiences with cancer and digital storytelling included a 3-page end-of-course written evaluation, a weekly story-showing log kept for 4 weeks post-course, a group teleconference held 1–2 weeks post-course, and a survey administered 6 months post-course. Participants described digital storytelling as a culturally respectful way to support cancer awareness and education. Participants described the process of creating digital stories as supporting knowledge acquisition, encouraging personal reflection, and sparking a desire to engage in cancer risk reduction activities for themselves and with their families and patients. As a result of creating a personalized digital story, CHA/Ps reported feeling differently about cancer, noting an increase in cancer knowledge and comfort to talk about cancer with clients and family. Indigenous digital stories have potential for broad use as a culturally appropriate health messaging tool.

Keywords

Alaska Native, community health workers, cancer education, digital storytelling, storytelling, health education, public health, health communication, Indigenous methods

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Introduction

Alaska is the largest state in the United States, one-fifth the size of the total landmass of the contiguous 48 states (State of Alaska, 2015). Alaska Native and American Indian people represent 229 federally recognized tribes in Alaska and account for approximately 19% of the state population (Bureau of Indian Affairs, 2016; U.S. Census Bureau, 2010-2014 American Community Survey). Over half of Alaska Native people live in 178 small, rural communities (U.S. Census Bureau, 2010 Census). Geographic remoteness significantly affects the ability of Alaska Native people to access the full spectrum of cancer care: education, prevention services, early detection, diagnosis, treatment, support services, and palliative and end-of-life care. Because Alaska communities have a small population, even a single person diagnosed with cancer can impact the community.

As recently as the 1950s, cancer was considered a rare disease among Alaska Native men and women (Lanier, Holck, Kelly, Smith, & McEvoy, 2001). By the 1990s cancer had surpassed heart disease to become the leading cause of mortality among Alaska Native people and remains so today (Kelly, Schade, Starkey, Ashokkumar, & Lanier, 2012). The four most frequently diagnosed cancers among Alaska Native people are colorectal, lung, breast, and prostate (Kelly

et al., 2012). Engaging in cancer risk reduction behaviors (American Institute for Cancer Research, 2015) and having recommended screening exams (U.S. Preventive Services Task Force, 2015) may reduce the burden of the most commonly diagnosed cancers among Alaska Native people.

There are 178 communities located throughout Alaska that are accessible year round only by air transportation. Communities are geographically separated from regional hospitals by immense areas of tundra, water, glaciers, and mountains. Specially trained community members called Community Health Aides and Community Health Practitioners (CHA/Ps) provide health care in Alaska's rural communities (Golnick et al., 2012). As clinical health care providers, CHA/Ps are required to have continuing education and frequently request cancer information.¹ During the 15 weeks of intensive CHA/P basic medical training, only 2 hours are devoted to cancer information (Community Health Aide Program, 2015).

To address this need for education and cancer information, story was identified by CHA/Ps as a preferred way of learning (Cueva, Kuhnley, Lanier & Dignan, 2007). Story as both form and method crosses cultural divides (Kovach, 2009), as realized by CHA/Ps who provide health care for community members from the 229 federally recognized tribes in Alaska. The tradition of storytelling is part of all Alaska Native cultures. Stories have been used to tell life lessons and pass on cultural values (Mayo & Natives of Alaska, 2002). Kovach (2009), an Indigenous educator and researcher, highlights the use of story as an Indigenous methodology; stories are a vessel for passing along teachings, medicines, and practices that can assist members of the collective. Jo-Ann Archibald (2001) reflects upon how stories capture our attention and ask us to think deeply and to reflect upon our actions and reactions, a process that Archibald calls "story work."

Digital storytelling is an innovative health messaging tool that provides a creative and engaging way for CHA/Ps to tell their stories and pass them on. It is portable and accessible, and it can incorporate web technologies and social media. Grounded in empowerment theory (Perkins & Zimmerman, 1995), digital storytelling combines a person's recorded voice with their choice of pictures, music, and transitions to bring the power of the media into the voices and hands of community health workers. Paulo Freire (2003), a Brazilian education theorist, advocated for empowering education that includes learners' thought and speech as the basis for social transformation. Since its inception in the early 1990s (Lambert, 2009), digital storytelling has gained momentum as an education (Matthews, 2014; Robin & McNeil, 2012) and health promotion tool (Gubrium, 2009; Wexler, Gubrium, Griffin, & DiFulvio, 2013).

Digital storytelling has been embraced by Indigenous communities as a way to combine storytelling traditions with modern technology to promote both individual and community health (Gray, Oré de Boehm, Farnsworth, & Wolf, 2010). Given the role of story in Indigenous communities, digital stories can be viewed as "the latest manifestation of a long tradition that

¹ In an unpublished survey (Cueva, 2009), 85 out of 85 Behavioral Health Aides and CHA/Ps requested cancer education, and 84 out of 85 wanted to learn more about cancer.

stretches back thousands of years” (Powell, Weems, & Owle, 2007, p. 12). Digital storytelling promotes creator control over the story’s structure and content, and consequently, digital stories created by, with, and for Indigenous communities challenge stereotypical representations of Indigenous people and provide an authentic reflection of traditional ways of knowing and being (Iseke & Moore, 2011). The creation of digital stories by Indigenous people can be beneficial both for the mental health of the storytellers, and as a culturally relevant way to empower individuals and communities towards health (Gray et al., 2010).

Throughout this 2-year project, we used a mixed-methods approach to listen to and learn from Alaska’s CHA/Ps about their experiences both creating a cancer-related digital story, and sharing their story’s cancer messages in their community and social networks. The project aim was to understand (a) how creating a cancer-related digital story affected Alaskan CHA/Ps’ cancer knowledge, attitudes, and health behaviors, and (b) how the CHA/Ps used their digital stories as health communication tools.

This research protocol was reviewed and approved by the Alaska Area Institutional Review Board and the Southcentral Foundation (SCF) Executive Committee and the SCF Board of Directors. Additionally, this manuscript was reviewed and approved by the Alaska Native Tribal Health Consortium (ANTHC) Health Research Review Committee (HRRC) on behalf of the ANTHC Board of Directors and the SCF Executive Committee and the SCF Board of Directors.

Methods

Four 5-day, in-person cancer education courses, utilizing the previously developed and evaluated “Path to Understanding Cancer” curriculum (Kuhnley & Cueva, 2011), were held in Alaska: two in Anchorage (March 3-7, 2014 and September 22-26, 2014), one in Bethel (October 13-17, 2014), and one in Nome (March 17-21, 2014). A total of 30 community health workers participated; the majority were female (26) and Alaska Native (24). Participants self-identified as Alaska Native (9), Yupik (7), Inupiaq (5), Siberian Yupik (1), Tsimshian (1), Tlingit (1), American Indian (1), Asian (1), and Caucasian (4). Participants ranged in age: 21-29 (10); 30-39 (5); 40-49 (5); 50-59 (6); 60-69 (4). The participants were from 21 different Alaska communities (see Figure 1), including 17 rural communities ranging in size from 42 to 829 people (U.S. Census Bureau, 2010 Population Finder). The majority of participants were Alaska CHA/Ps (25), and five people were employed in a variety of health occupations serving their communities (traditional healer, behavioral health aide, public health nurse, dietician, and health educator). Alaska CHA/Ps serve as rural Alaska’s primary care providers and take on similar roles as health educators and public health nurses. Consequently, we did not expect any differences in results between CHA/Ps and other community-based health roles. However, results were examined both among CHA/Ps alone and among all participants, with no substantial differences between the two groups. As a result, all results shared in this manuscript are drawn from the entire cohort of participants, allowing all voices to be heard.

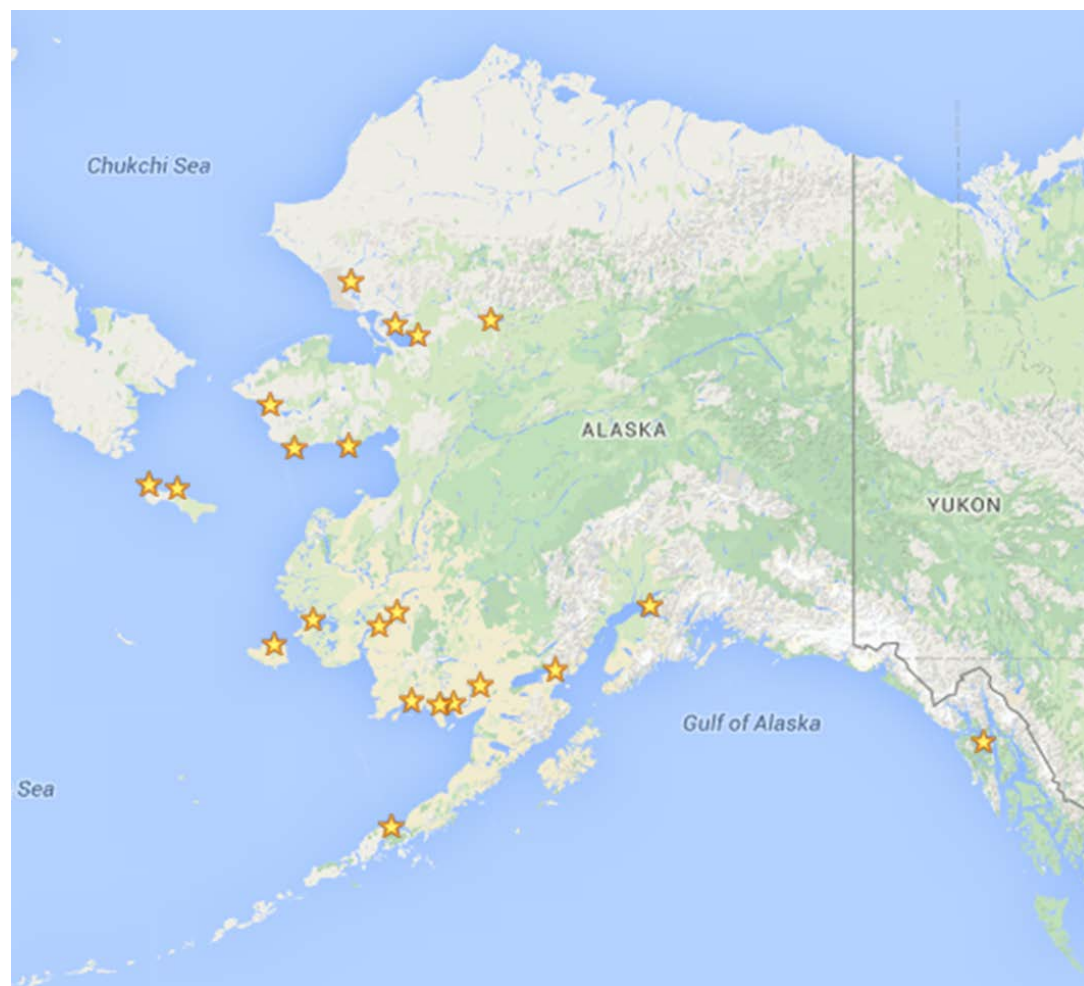


Figure 1. Map of Alaska: Stars denote participant communities.

Recruitment and Participants

Courses were advertised through existing Community Health Aide Program networks, including state wide email groups, newsletters, previous cancer education course participants, the Community Health Aide Association, and Community Health Aide Program leadership. Courses were provided in all three Community Health Aide Program training center locations, and training center program staff assisted with recruitment. CHA/Ps were selected for each course based upon their ability to actively participate in all course requirements, desire to learn about cancer, and support from their regional health corporation. Each class could accommodate 10 participants, and actual class sizes averaged 7.5 students. The attrition was due to a variety of factors including lack of funds to support CHA/P's travel to attend the 5-day course, the inability for CHA/Ps to be away from their village-based clinical practice, adverse weather conditions that prevented scheduled air travel, and sudden personal, family, or community illness.

As part of an application that CHA/Ps completed before attending the course, the CHA/Ps described their experiences with cancer and how they hoped to apply knowledge gained as a result of course participation. All respondents knew at least one person who had been diagnosed with cancer, and many reported providing health care for someone with cancer. In the words of one respondent:

In my life I am surrounded by cancer survivors and stories of cancer. This course provides me the incentive to learn about cancer and to learn how to make and tell a digital story. I want to help my community to have a better understanding of cancer.

Cancer Education and Digital Storytelling Course Overview

Course objectives were as follows: providing basic cancer information, introducing digital storytelling as a tool for promoting cancer awareness and cancer knowledge, developing participants' computer knowledge and skills to create a digital story, and assisting participants in developing a plan for showing their digital stories within their communities. The cancer education course included interactive learning that covered specific content based on course objectives. Cancer-specific content included: the causes of cancer; facts about cancer among Alaska Native people; healthy lifestyle choices to decrease cancer risk or prevent cancer; recommended screening exams to prevent cancer or detect it in early stages; cancer diagnosis and treatment; pain assessment and management; loss, grief, and end-of-life comfort care; and self-care for health care providers and caregivers.

The process of creating a personalized digital story in the cancer education course supported Alaska Native ways of knowing. The course included a story circle during which each participant shared the story they wanted to tell. Participants explored cancer information, reflected on their personal experiences, and envisioned how they might apply their knowledge to make a difference in cancer within their communities. A story circle, similar to a talking circle, may provide the first outlet for participants to acknowledge and create something positive from their experiences with cancer. Working with people to help them uncover meaning in their stories offers an opportunity for healing and hope as old stories are rewritten and new ones are envisioned (Gaydos, 2005). Stories may facilitate a personal journey of discovery by offering individuals a means of being understood, as well as helping to find meaning in their stories (Jones & Evans, 2008). Within the story circle, approaches to offer constructive suggestions for each other included "I really liked when ..." and "If this were my story ...". Story scripts were refined prior to audio recording by inviting creators to consider their "I" message: why they want to tell this story; who they identify as potential viewers; and what they hope viewers will learn/feel/do after watching their story.

Previous research identified that telling a personal story, accompanied by factual information and images selected by the storyteller, represented a strongly engaging approach to digital stories (Cueva et al., 2015). Windows Movie Maker (free computer software) was used to make each person's digital story. Participants recorded their written script (approximately 250 words) to give audible inflection to their personal story. Participants talked with and received

verbal permission from any people in the photos they wished to include in their story. Additionally, to protect against copyright infringement, public domain images and music were used. Upon completion of their digital stories, course participants chose how and in what ways they authorized the course instructors to share their stories. Participants could choose to sign a written authorization form approved by the Alaska Native Tribal Health Consortium granting the two course instructors permission to show their story and/or post their story on the Community Health Aide Program website.

As part of the cancer education with digital storytelling course, participants were engaged in an ongoing dialogue to help the investigators learn about their experience with digital storytelling. This included a 3-page end-of-course written evaluation, a weekly log for a total of 4 weeks after the course reporting story showings, a group teleconference held 1–2 weeks post-course, and a survey administered 6 months post-course.

End-of-Course Evaluation

All 30 participants completed a 3-page written evaluation on the last day of the 5-day in-person cancer education course. Participants reported their experiences with combining cancer education and digital storytelling by completing open-ended and check-box questions.

Group Teleconference

Approximately 2 weeks post-course, CHA/Ps were invited by email to participate in a group teleconference to share how and in what ways they may have shown their stories. Participants were invited to share any challenges they had experienced in sharing their digital stories, as well as their perspective on viewers' responses. Two teleconference dates were selected with participants at the end of the course to maximize teleconference participation.

Digital Storytelling Dissemination

Participants were each given a viewer log to track their digital story outreach. Log items included when and where the CHA/P showed their story, the number of viewers, and any challenges or reactions to the digital story. For 1 month post-course, CHA/Ps emailed a completed log to the primary course instructor at the end of each week. Each week, one name was randomly selected from those participants who completed a viewer log to receive a gift card.

Survey

A survey was administered 6 months post-course to learn CHA/Ps' experience of digital storytelling over time. The 23-question survey included Likert scale, check-box, and open-ended questions. Contact information was available for 27 of the 30 course participants at the time of survey dissemination, and each participant with contact information was sent an email that included a link to the online survey via SurveyMonkey. To prompt individuals to complete the survey, three email reminders were sent over the course of 1 month. A total of 19 participants (70% of those contacted) completed the survey. The majority of respondents were women (17) and Alaska Native (13); age ranges were 21–29 (3), 30–39 (3), 40–49 (4), 50–59 (5), and 60–69 (3) (one respondent skipped this item). Two \$50 gift certificates were given as a thank you to

two participants randomly selected from those who had chosen to provide their name and contact information for the drawing. No survey data were linked to participants' names or contact information, and all responses were reported anonymously.

Data Analysis

Both quantitative and qualitative data were collected from end-of-course written evaluations, group teleconferences, digital story viewer logs, and the 6-month-post-course survey. Survey responses were summarized in SurveyMonkey, and data were exported into a password-protected Excel spreadsheet for analysis. Additional information from the end-of-course evaluations, viewer logs, and group teleconferences was also entered into a password-protected Excel spreadsheet for analysis by the project team. The project team also reviewed qualitative responses to open-ended questions from all evaluation tools for common themes. These qualitative themes were shared by email with the course participants, who affirmed the findings.

Results

All 30 course participants integrated information presented during the course to create their own personalized, medically accurate, 2-to-3-minute digital cancer story to share with people in their communities. Digital stories for which the project team received storyteller permission to share publicly are located on the Community Health Aide Program website (<http://www.akchap.org/html/distance-learning/cancer-education/cancer-movies/digital-stories.html>).

Each participant's digital story incorporated one or more of the following components:

- ways cancer had touched their lives and/or the lives of those in their communities;
- cultural perspectives about cancer, reflecting cultural values, language, and traditions; and
- ways to promote health and wellness for cancer prevention and cancer risk reduction specifically for Alaska Native people.

In both the post-course telephone conversation and weekly written logs, CHA/Ps enthusiastically shared how they were showing their stories to family, friends, patients, and coworkers. Stories were shown on Facebook, YouTube, and other websites, and at a variety of community gatherings, tribal council meetings, health fairs, school classes, and even a regional basketball tournament. One month post-course, participants reported showing their digital stories over 57 times to more than 959 viewers.

Participants indicated that the process of creating a story provided an opportunity for them to gain insight into their own personal experience with cancer. They talked about creating digital stories as a way of "letting go" or a form of "emotional release." The following common themes emerged from course participants on their experiences creating and sharing digital stories.

Digital Stories Are Culturally Respectful

On the post-course evaluation, all participants reported that they liked combining digital storytelling with cancer education as a culturally respectful way to support learning. All 6-month-postcourse survey respondents also checked “yes” in response to the question “Do you feel digital stories are a culturally respectful way to share health messages?” Additionally, respondents affirmed that they liked digital stories as a way to support learning and as a health messaging tool:

Digital story is a unique way to share your own story and it is a powerful tool to promote health. Academic books don't have “emotions.” Digital stories are about education through your own emotion.

Culturally, story teaching has been our way of life. Digital stories allow us to share with more people about our way. A lot of natives have a better understanding of cancer from other natives and the wording is so much easier to understand than all the medical language that providers use.

Creating Digital Stories Enhances Learning

Participants emphasized the capacity of story to connect with people both affectively and cognitively, and they discussed how the process of creating digital stories increased knowledge acquisition and understanding.

All the cancer education was great, but I learned the most from the other participants and their stories. People connect by story. Stories can be passed on.

You can watch it over and over and it still would be informative. Unlike reading a pamphlet over and over. Not everyone (myself) wants to do that. I never remember most of the information I read. A movie has pictures associated with the words said.

Participants were asked to rate their knowledge of cancer both before and after course participation using a 5-point Likert scale, with 1 being *not knowledgeable*, 3 being *somewhat knowledgeable*, and 5 being *very knowledgeable*. Before the course, participants reported feeling less than somewhat knowledgeable (2.8; see Table 1). After the course, participants reported feeling very knowledgeable (4.2). This change reflects an average increase of 1.4 on the 5-point scale.

Table 1
Cancer Knowledge Self-Assessed Before and After Cancer Education Course

Question	Number of participant responses					Avg. scale value
	1 (<i>Not knowledgeable</i>)	2	3	4	5 (<i>Very knowledgeable</i>)	
BEFORE taking this cancer education course with digital storytelling, how would you rate your knowledge of cancer?	2	2	12	3	0	2.8
AFTER taking this cancer education course with digital storytelling, how would you rate your knowledge of cancer?	0	0	3	10	6	4.2

Detailed written responses substantiated the quantitatively reported knowledge gain:

Now after taking the class I was able to help my Dad get treatment for the skin cancers that had reoccurred on his back. I don't feel scared of cancer now that I know something of the treatments available and that people are successfully treated.

I have a feeling I had some of the knowledge, but the course made me feel more comfortable in asking certain types of questions from doctors, and then finding a way to explain it easier to my patient. It's also given me a boost of confidence to actually talk more about my patients' feelings.

Before I hated the word cancer—it brought me to the worst days of my life taking care of my father at his end of life care. Now I am able to beg patients without crying and do it professionally for them to get early screening. Knowing early detection is key to beating cancer. This class taught me to look at something dark in my life and turn into a place where I can now face cancer.

Creating Digital Stories Increases Comfort Talking About Cancer

At 6 months post-course, survey respondents were asked to rate their comfort with talking about cancer both before and after the cancer education course on a 5-point Likert scale, with 1 being *not comfortable*, 3 being *somewhat comfortable*, and 5 being *very comfortable*. On average, respondents rated their comfort with talking about cancer a 2.3 prior to taking the course and a 3.9 as a result of course participation, as shown in Table 2. This reflects an average participant shift of 1.6 on the 5-point scale.

Table 2
Comfort With Talking About Cancer, Self-Assessed Before and After Cancer Education Course

Question	Number of participant responses					Avg. scale value
	1 (<i>Not comfortable</i>)	2	3	4	5 (<i>Very comfortable</i>)	
BEFORE you participated in this cancer education course, how comfortable were you with talking about cancer?	6	4	7	2	0	2.3
Now, AFTER participating in this cancer education course, how do you rate your comfort with talking about cancer?	0	3	3	5	8	3.9

Additionally, respondents wrote in-depth comments describing changes in comfort talking about cancer as a result of participating in the cancer education and digital storytelling course:

It was very emotional. I was able to release what I had bottled up. It helped me feel comfortable to talk about cancer, and help me accept it. I found the courage to speak to my patients, family, friends with my new knowledge of cancer.

Cancer is a big scary topic. When someone hears cancer, they automatically think that it IS their death. Patients don't automatically think they can overcome it. But in our village, it seems as though you hear more about people dying from cancer than surviving cancer. Not an easy topic.

I am doing it now [talking about cancer]; the class gave me confidence.

Felt like talking about cancer when someone came home was taboo, and did not really know how to help now I have an idea. With our digital stories, I feel that it helps people not to be afraid to go out and get screenings done.

I am very pleased and able to associate comfortably with people who were previously diagnosed with cancer, whereas before it was very difficult, I did not know how to treat them ... how to associate or how to talk to them.

Story creators also commented that, although cancer and cancer risk reduction behaviors can be difficult to talk about, a digital story can be used as a tool to begin the conversation. Participants also mentioned that digital stories could be widely distributed as health messages, potentially reducing the expenses of travel to disseminate cancer education:

Digital storytelling reaches more people and can be replayed to affirm messages.

Opened up a new door for patients to talk about it [cancer] freely.

Digital Stories Inspire Behavior Change

On the end-of-course evaluation, 27 of the 30 participants reported that, as a result of creating their own digital story, they found positive ways to take care of themselves, their patients, their families, and their communities. Written responses included talking about and encouraging cancer risk reduction behaviors, such as quitting commercial tobacco use, having recommended screening exams, eating less processed food, and increasing physical activities:

While my digital story was in the process of coming together, I started to realize how cancer has really affected me and has hurt me. During class I decided to quit smoking.

Eat healthier, rest more, exercise more, quit smoking

Make mammogram appt

After completing their stories, CHA/Ps responded in writing to the following prompts: “I told this story because ...” and “After watching my story, something I hope you think about ...” In response to these questions, participants shared that their stories were personalized calls to action:

I come from a very small village but we have seen more than our share of cancer. I told this story because not a lot of people know about cancer or the things some go thru. After watching my story, I hope you think about getting your screenings or making an appointment to get screened.

At 6 months post-course, survey respondents reported changes in the ways they and their families took care of their health. In response to the question “As a result of creating your own digital story, do you do anything differently in the ways you take care of your health?”: nine people had received a recommended cancer screening exam, one person stopped using commercial tobacco, two people cut down on their commercial tobacco use, eight people increased their physical activity, and 11 people were eating healthier. A total of 12 survey respondents also reported family members doing something different as a result of the course, including trying to quit cigarette smoking, getting a recommended cancer screening exam, and eating healthier.

Digital Stories Are Enthusiastically Shared With Communities

At 6 months post-course, all respondents reported having shown their digital story, with the digital stories shown a combined total of over 94 times. Individual participants reported showing their story from 2 to 12 times or more, with several people writing “lots” and “many” for the number of times they’d shared their story. The number of viewers per showing ranged from four to more than 50 people, with additional written responses including “many people” and “everyone at home and work.” One respondent reported showing their digital story “maybe

at least 13 times a week. My kids love it and they're always playing it almost every day.” Respondents reported showing their stories to family, friends, coworkers, youth, elders, patients, and community members. Participants reported showing their story in the clinic, at family gatherings, and during community presentations, as well as posting their stories on Facebook and the web. CHA/Ps reported that viewers liked their stories, recognized the importance of eating healthy diets and getting screened, and were motivated to make changes. Viewers also told their own stories about cancer and offered suggestions for future showings (e.g., TV screens in the hospitals). In the words of CHA/Ps:

I think the most important part of the digital storytelling is the sharing with our communities after the class is over. Digital stories are very inspiring and promote healthy living. I find it easier and straight to the point and much better to get the message across to people. I'm not very good at public speaking and it speaks for me.

These stories are created by us—sometimes we make a big impact in people's lives without knowing it. This allows us to take these movies home and show them to our families and people within our community. Some people don't read too good and it helps them understand when we do the stories. It opens them up to ask questions and to understand more.

Limitations

Only a small number of community health workers from throughout Alaska were able to participate in the cancer education course to create their digital story. Consequently, participants' experiences, as reported within this paper, may not be representative of all CHA/Ps and other individuals working in community-based health. Expanding the reach of cancer education and digital storytelling to involve more individuals could strengthen both the impact of culturally specific health messaging and the potential to evaluate the effect of cancer-related digital stories in Indigenous communities. Due to the small size of Alaska communities, digital stories were most often shown to people known to the storyteller, and viewer responses may differ if there is not an established relationship with the story creator. Gaining feedback from viewers both known and unknown to the story creators could potentially elucidate the impact of personal relationships on viewers' perceptions of the stories.

Discussion

Digital stories created by Alaska's CHA/Ps were a culturally respectful way to enhance learning, increase cancer knowledge and comfort to talk about cancer, and inspire behavior change to reduce cancer risk. Additionally, CHA/Ps enthusiastically shared their digital stories as health communication tools to increase cancer awareness and promote cancer risk reduction behaviors among Alaska Native people. Digital storytelling holds promise to make a significant contribution to reducing cancer disparities in global Indigenous communities by providing a traditional, and uniquely modern, way to share authentic stories of culturally prioritized health

messages. The digital stories produced by Alaska's CHA/Ps incorporated dynamic lived experiences of culture and health, transformed within the relational context of community.

Indigenous communities with traditions of storytelling, and a movement towards technology, may find creating and sharing their prioritized health messages in the form of digital stories a pathway to community empowerment and health transformation. Digital storytelling promotes creator control over the story's structure and content, and consequently allows communities to incorporate both traditional ways of knowing and contemporary health priorities into their messages. Expanding CHA/Ps' access to cancer education and digital storytelling could further enhance their community impact.

Digital storytelling was described by respondents in this study as a culturally respectful way to support cancer awareness and education, with sustained usefulness for themselves and their communities. As a result of creating a personalized digital story, CHA/Ps reported feeling differently about cancer, noting an increase in cancer knowledge and comfort to talk about cancer with clients and family. This shift was noted on the end-of-course evaluations and affirmed by respondents on the 6-month-postcourse survey. Throughout project evaluation, participants described how the process of creating a digital story supported knowledge acquisition and personal reflection, which often sparked emotional healing as well as a desire to engage in cancer risk reduction activities for themselves and with their families and patients.

With their cultural relevance, brevity, reproducibility, and flexibility, digital stories have the potential to be widely translated into diverse settings and locales, increasing their impact potential. Digital stories are relatively inexpensive to create and reproduce, increasing both ease of dissemination and adaptability for other health-related topics and populations. Indigenous digital stories have the potential to open cancer conversations and impact cancer prevention and detection behaviors to change the story of cancer among Indigenous people. This research serves as a strong foundation for future behavior intervention research using Indigenous digital stories as health communication tools to impact Indigenous health.

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Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care

Abstract

This paper describes the development and implementation of a community-based palliative care program in Six Nations of the Grand River Territory, Ontario, Canada. Six Nations' innovative program is grounded in a vision to provide access to quality palliative care at home and incorporate Haudenosaunee traditional teachings. A community-based Project Advisory Committee led the development process, and a Leadership Team of local and regional palliative care partners led implementation. Using participatory action research, academic researchers supported activities and facilitated data collection and evaluation. Outcomes included: creation of a Palliative Shared Care Outreach Team, including a First Nations physician, nurse, and social worker; development of a detailed care pathway for clients who need palliative care; increased home deaths (55) as compared to hospital (22) or hospice (6) deaths; access to palliative care education and mentorship for local healthcare providers; incorporation of traditional teachings to support clients and staff dealing with death, dying, grief, and loss; and creation of a palliative care program booklet for Six Nations Health Services. This unique initiative reduces disparities in access to quality palliative home care and demonstrates that First Nations communities can successfully undertake a process of community capacity development to create unique and culturally responsive palliative care programs. Challenges included overcoming federal and provincial jurisdictional issues in provision of health services through collaborative partnerships at the local and regional level.

Keywords

Aboriginal, First Nations, Indigenous, end-of-life care, supportive care, palliative care, community capacity development, shared care outreach team, Haudenosaunee traditional teachings

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Holly Prince, MSW, co-investigator and project manager of the EOLFN research project, Anishinaabekwe of the Red Rock Indian Band. Holly worked closely with Lori and Verna on this research from 2010 to 2015, guiding data collection and consulting on implementation issues as they arose. Holly provided recommendations for the content of the article, reviewed all drafts, and approved the final article.

Mary Lou Kelley, MSW, PhD, is a professor emeritus of the School of Social Work at Lakehead University, Thunder Bay, Ontario, and the principal researcher of the CIHR-funded project. Mary Lou guided all aspects of the research over the 5 years. She collaborated closely with Verna throughout the writing of the article and edited the final draft. Contact information: Centre for Education and Research on Aging & Health, Lakehead University, Thunder Bay, Ontario, P7B 5E1. Phone: 807-472-7224; Fax: 807-766-7222; Email: mlkelley@lakeheadu.ca

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Introduction

Supporting dying community members and their families in their wish to come home to the Six Nations of the Grand River Territory at the end of life motivated the work being shared. This article reports the experience of Six Nations of the Grand River, Ontario, Canada, in successfully developing and implementing an innovative palliative care program that is uniquely adapted to their community, culture, and regional context. Their palliative care program model is grounded in community values and Indigenous culture, and it successfully supports people to receive their care and die at home if that is their wish.

The palliative care initiative in Six Nations began in 1999 with the establishment of the Home and Community Care (HCC) Program, funded by Health Canada, First Nations and Inuit Health Branch. The program was further developed and formalized (2010–2015) through a collaboration with the Improving End-of-Life Care in First Nations Communities (EOLFN)

research project, based at Lakehead University, Thunder Bay, Ontario (see www.eolfn.lakeheadu.ca). The palliative care initiatives in Six Nations are ongoing and have now been integrated into existing community health services and regional palliative care programs.

This article shares the story of developing palliative care in Six Nations of the Grand River Territory. The story is told from the perspective of the community facilitator, Verna Fruch, and community lead, Lori Monture, in collaboration with two members of the research team (Prince and Kelley). The purpose of the article is to enhance understanding of how other communities can incorporate dying within a First Nations wellness tradition that focuses on providing quality of life to the end of life. Other First Nations communities may be inspired by this example to undertake their own community development process and build local capacity to provide palliative care.

The Haudenosaunee Philosophy as the Program Foundation

When we are born the Creator gives us that first breath ... and when we die, he takes it back. (Six Nations Traditional Knowledge Carrier)

This statement provides the cultural foundation for developing the palliative care program in Six Nations of the Grand River. It captures the essence of the traditional philosophical values in the Haudenosaunee (People of the Longhouse) philosophy statement (Six Nations Palliative Care Leadership Committee, 2015). Dying is understood as part of the cycle of life, and people take their place in relation to all of Creation. Acceptance comes from a view of the natural order that accepts and celebrates that we are given life. We exist with purpose and a duty to uphold the human responsibility to all of Creation until the time when the Creator takes back our life.

The Six Nations community desired to return to the traditional acceptance of death and dying as part of the life cycle. It was this desire that motivated local healthcare providers to develop a palliative care program in their community, as illustrated by the comments below:

Traditionally, our birth was announced to the universe when our mothers went into nature and our birth fluid seeped into the earth, and we were named and celebrated. Now as we make our journey back to the Creator, we have lost that acceptance and we struggle with the natural order. Our community is telling us that we need to regain our acceptance of death and dying, and we need to help each other through this transition and provide supportive care as is done at birth. (Traditional Knowledge Carrier as told to Six Nations community facilitator)

It is our intention [as healthcare providers] to support our cultural practices to help individuals achieve a sense of peace and well-being while they are preparing for their journey back home.

Sacred knowledge may be different as variances arise from the family, the Longhouse, the Nation and the community (Martin, 2009, p. 2).

Palliative Care and End-of-Life Care

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2015). End-of-life care is the final phase of palliative care when dying is imminent and inevitable (Canadian Hospice Palliative Care Association, 2013), and normally requires enhanced services and support for the person and family.

Historically, palliative care has focused mainly on people with terminal cancer, a focus that has resulted in a misperception by some that palliative care is only appropriate for people suffering from a terminal illness, is only for the last few weeks of life, and is provided mainly by highly specialized teams and programs (WHO, 2004). The Canadian Hospice Palliative Care Association (2013) emphasises that palliative care is appropriate for all people and their families who are living with a life-threatening illness due to any diagnosis, including but not limited to cancer. The palliative approach can be provided concurrently with treatment and chronic disease management (Boland & Johnson, 2013; Coventry, Grande, Richards, & Todd, 2005; Murtagh, Preston, & Higginson, 2004; WHO, 2004).

The Need for Palliative Care in First Nations Communities

The need to develop appropriate palliative care programs for First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal illness. In their population study, Statistics Canada (2011) projected that among those of Aboriginal identity, the number of persons aged 65 and over will more than triple from 4.7% in 2006 to 15% in 2031. Older First Nations people have a higher prevalence of a number of health conditions when compared to the age-adjusted Canadian adult population. These include: arthritis/rheumatism (25% vs. 19.1%), hypertension (20.4% vs. 16.4%), asthma (9.7% vs. 7.8%), and heart disease (7.6% vs. 5.6%; First Nations Information Governance Centre [FNIGC], 2007). Rates of diabetes are reported as being more than 3 times higher than in the Canadian population (20.7% vs. 6.2%) with over three quarters (80.8%) having the Type 2 variant (FNIGC, 2012). The prevalence of chronic illness increases with age, with approximately half of First Nations people aged 60 years or older reporting four or more chronic health conditions (FNIGC, 2012). In sum, palliative care programs in First Nations communities are required to address multiple and complex health issues.

While cancer is a major cause of death among older Canadians, other major causes of death are heart disease, stroke, and respiratory diseases (Wilkins, 2006). These trends are reflected in the First Nations population as well. A recent report that focused on First Nations health status in Alberta noted that ischaemic heart disease, cancer, COPD, and diabetes are among the leading causes of death for seniors 65 and up (Health Canada, 2012). Thus, palliative

care programs for First Nations people must focus on caring for people who are dying primarily of chronic disease. Fortunately, within the last 15 years, the scope of palliative care has evolved to be much broader than cancer care (Ferris et al., 2002).

The Six Nations Community and Health Services Context

Six Nations includes the Mohawk, Cayuga, Onondaga, Seneca, Oneida, and Tuscarora Nations that were unified in 1722 (National Park Service, 2015) under the Great Tree of Peace (Parker, 1912). During the American Revolution, Captain Joseph Brant led many from the Iroquois Confederacy to ally with the British. For their loyalty to the Crown, the Mohawks and such others were deeded a tract of land along the Grand River of approximately 18,000 hectares, bounded by Brant County and Haldimand County (National Park Service, 2015). The main reserve is located approximately 25 km southwest of the city of Hamilton, Ontario. Six Nations has the largest population of all First Nations communities in Canada, and as of December 2013, the total band membership was 25,660, with 12,271 living within the reserve (Six Nations of the Grand River, 2013). Six Nations Health Services employs about 300 staff.

The Six Nations Palliative Care Program is situated within the Long Term Care/Home and Community Care Program. The Palliative Care Program vision includes providing compassionate, coordinated, and comprehensive end-of-life care to individuals living in the community of Six Nations (Six Nations Palliative Care Leadership Committee, 2015). Services include: case management; physiotherapy; occupational therapy; health advocacy; nursing; adult day centre; personal support services, community support services; supportive housing; traditional wellness coordinator; Traditional Knowledge Carrier; family health team; and a medical centre that includes dental and public health staff, a physician, and a pharmacy (<http://eolfn.lakeheadu.ca/develop-palliative-care-programs-workbook>). The program is rooted in the following Haudenosaunee philosophy statement:

Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton karihwatehkwen or the words that come before all else are a reminder of the place that we as human beings were meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions and is expressed in our annual cycle of ceremonies of Thanksgiving. Our worldview teaches us that we exist on purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee Tradition, acceptance comes from a view of the natural order that accepts and celebrates the coexistence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address “we must see the cycle of life continue”

and ensure the health and wellness of the people (Six Nations Palliative Care Leadership Committee, 2015, p. 3).

Healthcare providers in Six Nations recognize that offering people the choice to die at home on the territory provides community members familiarity, comfort, and access to culturally appropriate services. Care at home can be provided by people you know, and transportation to external health services is not such a burden. Dying at home helps to retain a person's dignity until the end of life by having frequent access to family, friends, and community members. The community is very important when someone is dying and offers support both to the dying individual and to their family.

Home and Community Care Services

In 1999, the Canadian federal government established the First Nations and Inuit Home and Community Care (HCC) Program, which has been designed to provide basic home and community care services to First Nations and Inuit communities (Health Canada, 2009). The program is funded using a population-based formula that has not been adjusted for increases in population, population aging, or changing health status since 1999. In most First Nations communities, the limited funding allows for services only during the day, Monday to Friday.

The HCC program is funded to provide nine essential service elements: client assessment; managed care; home care nursing; home support personal care; in-home respite; linkages; medical equipment and supplies; capacity to manage program delivery; and record keeping and data collection (Health Canada, 2009). Where communities provide all the essential service elements and if funding remains available within their approved budget, the HCC program allows communities to implement additional supportive service elements. These supportive services may include but are not limited to: home-based palliative care; adult day care; meal programs and rehabilitation and other therapies (Health Canada, 2013). Therefore, First Nations and Inuit Health Branch does not fund palliative care as a unique program; however, the essential services required to provide home-based palliative care are funded (i.e., case management, nursing, personal care).

The implication of this funding situation is that communities that wish to provide palliative care can do so; however, they need to have the required resources within their existing budgets. First Nations communities may also augment their services through the creation of health service partnerships (Health Canada, 2013). Examples of service partnerships that could be created to provide palliative care are with provincially funded hospices, home care programs, or palliative care programs. These were the partnerships formed in Six Nations of the Grand River Territory by the HCC program.

Community Capacity Development to Create Palliative Care Programs

The approach taken by the Six Nations community members to develop their palliative care program was based on a model of rural community capacity development created by Kelley (2007; Kelley, DeMiglio, Williams, Eby, & McIntosh, 2012) and introduced to the community

by the EOLFN research team. Members of the Six Nations community adopted this model as a guide for developing their palliative care program, adapting it to culture and local circumstances.

In this model, developing a community palliative care program is locally initiated and driven. It requires dedication, leadership, and commitment from key community members and local healthcare providers. The process of creating change is from the bottom up and it takes time (years). The program builds on what already exists, strengthening and adapting resources, services, and relationships when required. Change takes place in four incremental phases (see Methods), each phase building on the previous work accomplished. However, it is a dynamic rather than a linear process. Progression through the phases is controlled by community members but is influenced by internal and external barriers, supports, and resources. Efforts to shape and manage these influences are the “work” in capacity development. Key aspects of the process are summarized below.

Prior to beginning, there are some required antecedent conditions for success. Communities need to have sufficient infrastructure, such as health services and providers, to provide palliative care. A shared vision for change in the care of dying people is important, and implementation of the program relies on effective collaboration among community healthcare providers and members. Finally, community members need to feel empowered to take action to achieve their vision, addressing gaps and challenges along the way. Early community work can focus on strengthening antecedent conditions if required.

A local person or event provides a catalyst for change that mobilizes community members into action. The program development process begins with establishing a local committee or resource team. Getting the “right” people involved is critical—people with influence, skills, and access to community resources. The palliative care committee assesses current community capacity and unmet needs and creates a program guide. Implementation involves growing the local palliative care program using five strategies: building community relationships; providing education to local healthcare providers and community members; providing palliative care (learning by doing); creating external linkages with regional palliative care resources; and advocating for quality palliative care.

Six Nations’ experience implementing the community capacity development process is described in the following section.

Methods

Development of the Six Nations Palliative Care Program (2010–2015) evolved from earlier work done both by healthcare providers at Six Nations and by the Lakehead University research team in northwestern Ontario. This earlier work provided a solid foundation for the collaboration between the Six Nations healthcare providers and EOLFN researchers. The focus of the work was developing palliative care at the community level.

Foundational Work in Six Nations of the Grand River Territory

In Six Nations, there was a strong interest in and commitment to supporting community members to come home to die. As a result, an internal palliative care committee was developed during 1999–2003 within the Long Term Care/Home and Community Care program. In 2005, an Indigenous graduate student, Valerie O'Brien, began a study to examine Six Nations' existing palliative care services, including the strengths, barriers, and challenges (O'Brien, 2012). This graduate student's research provided valuable information to the Six Nations healthcare providers by identifying where the current palliative care system needed to be improved. Later, the graduate student was invited to become, and became, a member of the EOLFN research team.

In 2004, the province of Ontario launched an End-of-Life Care Strategy that was implemented by each of the 14 Local Health Integration Networks (LHIN), which are the funders of all provincial health services for the region. Six Nations healthcare providers became actively involved with their LHIN (LHIN 4) and their regional End-of-Life Care Network in an effort to further their efforts in palliative care. The Network formed an Aboriginal Hospice Palliative Care Services Committee to work towards designing and implementing a service delivery model for First Nations communities within the region. Six Nations hosted a LHIN-wide regional planning meeting in December 2010, with the goal of requesting community and healthcare provider input to establish priorities in care provision, and to strengthen the networks involved in providing care to Aboriginal clients. This LHIN-supported regional work served to engage regional healthcare providers and generated a higher level of awareness of the issues and needs related to providing palliative care in First Nations communities. The EOLFN research team was invited to attend and participated in that planning meeting.

This regional work done by Six Nations with the LHIN and End-of-Life Care Network built many important relationships, including one with Stedman Community Hospice/St. Joseph's Healthcare Foundation in nearby Brantford, Ontario. Stedman had a well-established inpatient hospice and was the hub for a regional shared care outreach team that offered palliative home care (<https://www.sjlc.ca/>). To enhance home care, Six Nations also developed a memorandum of understanding with the Brantford Community Care Assess Centre (CCAC) to collaborate on providing palliative home care in Six Nations. The CCAC is funded by the Ontario Ministry of Health to coordinate and fund nursing services, medical equipment, and supplies for all palliative clients who choose end-of-life care in their homes or residential hospices. A CCAC community care coordinator visited Six Nations biweekly to discuss clients in need of palliative home care services with HCC staff. CCAC then provided the necessary acute nursing services, medications, and equipment, and coordinated care provision with HCC providers. These strong relationships and collaborations became critical to the future success of the Six Nations Palliative Care Program.

The Research Partnership to Develop Palliative Care in Six Nations

In 2009, Six Nations partnered with the researchers and three other First Nations communities to apply for a participatory action research (PAR) project that was funded by CIHR from 2010 to 2015. The goal was to develop culturally appropriate palliative care programs using a process of community capacity development in four partnering First Nations communities that would each serve as case studies. Over 5 years, using the EOLFN community capacity development process, each of the four partnering First Nations communities created a unique community-based palliative care program suited to their culture and context. The learnings from the four communities were used to create knowledge, tools, and resources for other First Nations communities.

The overall goal of PAR methodology is to create social change. PAR differs from more conventional research in that the participants (the community) and not the researchers retain control of all aspects of the process. Relationships are collaborative partnerships where researchers and participants bring their expertise together to achieve their common goal (Minkler & Wallerstein, 2002). Using the PAR approach, knowledge about how to build community capacity in palliative care was co-created by the researchers and the Project Advisory Committees in the four communities. Research involved using a reflective spiral of activity involving: identifying a problem, planning a change, enacting the change and observing its consequences, reflecting on these processes and consequences, and preplanning, acting, observing, and reflecting (Kemmis & McTaggart, 2000). In the overall EOLFN project, promising practices drawn from the work have been shared with other First Nations communities through a workbook of research-informed community capacity development strategies (EOLFN [Improving End-of-Life Care in First Nations Communities Research Team], 2015).

It is the process of change that is the essence of the PAR methodology and the community capacity development model. There were four overall phases to the EOLFN research:

1. Conducting a community needs assessment and creating recommendations.
2. Developing work plans to implement identified strategies.
3. Implementing and evaluating each strategy.
4. Disseminating the outcomes to community members, healthcare decision makers, and other First Nations communities.

Throughout this research, the change process and its outcomes were documented. Please visit the project website for further information on the overall project activities (www.eolfn.lakeheadu.ca). The focus of this paper is how Six Nations moved through their process of change and the outcomes specific to their community.

Implementing the Research Process

Approval for the EOLFN research was gained from the Six Nations Research Ethics Board as well as the Lakehead University and McMaster University Research Ethics Boards. The project followed OCAP principles of ownership, control, access, and possession (FNIGC, 2014).

The community established a Project Advisory Committee that consisted of Six Nations health and social care leadership, chosen by the health director. Members included the manager of the Six Nations Long Term Care/Home and Community Care Program; chair of the HCC Palliative Care Committee; the Six Nations community facilitator; executive director of the Family Health Team; and ex officio the director of Six Nations Health Services. Lori Monture, manager of Long Term Care/Home and Community Care, was chosen to be the community lead for the EOLFN project and to chair the Project Advisory Committee. The Project Advisory Committee's role was to oversee and guide all aspects of the research including: assisting with community engagement, identifying appropriate key informants and participants, reviewing preliminary data interpretations, and developing an inclusive dissemination plan. The committee also ensured that any decisions complied with the Six Nations Council Research Ethics Committee and assured that appropriate respect was given to Haudenosaunee culture, language, knowledge, and values. All cultural knowledge shared through the research was shared with permission of the Traditional Knowledge Carriers.

The community lead described how the Project Advisory Committee consulted with the Traditional Knowledge Carriers:

Initially we asked our traditional wellness coordinator, a staff member of the Home and Community Care Program, to research and consult with the local Traditional Knowledge Carriers on palliative care. Once it was time to share information, she worked with them and they gained "approval" from their peers (who were the Clan Mothers, chiefs, and Faithkeepers as well as other Traditional Knowledge Carriers) on what could be shared. There is an understanding that this is ancient wisdom and is very sacred; we must protect it and use it in a most respectful manner. We would not misuse the information or exploit it, for it to continue to be effective as it was intended to be. We have embraced the Traditional Knowledge Carriers in the work that we do and now they understand that it is important to teach the coming faces and are more willing to share the ceremonies with us. (Manager, Long Term Care/Home and Community Care)

The EOLFN research team paid for a local community facilitator, selected by the Project Advisory Committee, to assist them to document the process and outcomes of the research. Verna Fruch, a member of Six Nations and an experienced home care case manager, was hired as the community facilitator. With guidance from the research team and direction from the Project Advisory Committee, Verna facilitated the community development process, collected data, and participated in qualitative data analysis by validating transcribed interviews and focus groups, and interpreting community context. She assisted the Project Advisory Committee to organize meetings, take minutes, and disseminate information.

Developing Palliative Care in Six Nations

The priority of the Six Nations Project Advisory Committee was to create a Palliative Shared Care Outreach Team in the community that would be available 24 hours a day, 7 days a

week, and provide medical, spiritual, and cultural support to dying people and their family members. It was perceived by the community that having such a palliative care team would enable people to have the choice to die at home if that was their wish, something that was not currently possible given limited resources. The community needs assessment indicated insufficient nursing services, especially during evenings and weekends. Further, there were needs for more culturally sensitive care that incorporated traditional medicine and culturally appropriate grief support for families and healthcare providers following a death.

To achieve their goals, the Project Advisory Committee created a Leadership Team of 20 internal and external healthcare providers who provided services to people living in Six Nations. This Leadership Team was responsible for the planning, education, and evaluation components of the Palliative Care Program. The team focused on four areas: identifying common issues/concerns and coming up with solutions; promoting educational opportunities for care providers; increasing public awareness of the availability of palliative care in community; and developing a care pathway and other protocols for the clinical teams. A detailed work plan was created that included seven objectives, each with detailed activities, a budget, time frames, and planned outcomes. This work plan guided the Leadership Team's work over the next 3 months.

The initial step in the work plan involved securing funding for a palliative shared care team in Six Nations from the LHIN. Palliative shared care teams are usually composed of a palliative care physician(s), nurses, social workers, and case managers, as well as primary care providers such as family physicians (DeMiglio & Williams, 2012; Seow et al., 2014). Palliative care specialists provide consultation, and there is 24/7 access to specialist clinician support for pain and symptom management, as well as psychosocial/spiritual and bereavement support. A multidisciplinary team approach is used and the family is considered a major part of this team, with a major emphasis on palliative care education (Seow et al., 2014).

With the needs assessment data in hand and the partnerships in place, LHIN funding to create a Palliative Shared Care Outreach Team in Six Nations was secured for 1 year. It was agreed that this funding would flow directly from the LHIN to the Six Nations community who in turn would pay Stedman Community Hospice for their services. A memorandum of understanding was developed between Six Nations and Stedman to detail the working relationship and mutual expectations.

Palliative Shared Care Outreach Team members were recruited next. The Family Health Team physicians at Six Nations agreed to participate in the new Palliative Shared Care Outreach Team and to be mentored by the Stedman Hospice Outreach Team physicians. A key component of the functioning of a palliative shared care team is the role of the palliative physician, and specifically for this team, an Aboriginal physician. A compensation package for the physician's time spent in mentorship and on call was agreed upon. The interested physician also agreed to attend an accredited palliative care education course.

The new positions of clinical nurse specialist and psychosocial spiritual bereavement clinician were filled next by an Aboriginal nurse and a social worker, both well-qualified community members. Their position descriptions were adapted from the regional palliative care

program to encompass the Haudenosaunee philosophy. Members of the new Six Nations palliative care team then began a 1-year mentorship experience with the physicians and staff at Stedman Hospice.

Three months after receiving funding from the LHIN, the Six Nations Palliative Care Program and team began receiving referrals for their community members from the regional palliative care program and, under the mentorship of Stedman Hospice, began providing palliative home care services. More details of the mentorship process and experience are included in the next section.

Outcomes

In May 2013, the first opportunity to bring a community member back to the territory to die occurred, and the newly created palliative care guidelines and client care pathway were put into effect. The experience of caring for this client at home was gratifying for all members of the new palliative care team, and the family was grateful for the professional care that they received. In terms of the research, all activities developed by the local Project Advisory Committee and Leadership Team were successfully implemented. Specific research outcomes included: creation of the Palliative Shared Care Outreach Team, including a First Nations physician, nurse, and social worker; development of a detailed care pathway for clients who need palliative care; increased home deaths as compared to hospital or hospice deaths; increased access to palliative care education and mentorship for local healthcare providers; incorporation of traditional teachings to support clients and staff dealing with death, dying, grief, and loss; and creation of new palliative care program guidelines within Six Nations Health Services.

1. Creation of the Palliative Shared Care Outreach Team

The Palliative Shared Care Outreach Team consisted of three healthcare professionals: a physician employed by the Six Nations Family Health Team, a clinical nurse specialist, and a psychosocial/spiritual worker employed full time on the team. All were Six Nations community members. The Six Nations community facilitator described the creation of the team as the most significant accomplishment:

I'd have to say the community outreach team is the most important because ... of being able to bring community members back home and to pass away in their own community.

The benefits of having the palliative care team are as follows: community members now have access to round-the-clock care; people are assisted with pain management; the team can manage complex care needs; the physician makes home visits; hospital emergency room visits are reduced; the risk of dying in hospital (rather than at home) is lowered; community members are able to die peacefully in their own home; the team links the community to external care providers to ensure client-centred care. Team roles are described in Table 1.

Table 1

Roles and Activities of Palliative Shared Care Outreach Team Members

Palliative care physician	<ul style="list-style-type: none"> ▪ receives referrals from family MD or specialists and collaborates with family MD, CCAC, Cancer Clinic, and community agencies to manage pain and symptoms ▪ makes home and hospice visits with clinical nurse specialist and provides psychosocial support on as-needed basis ▪ takes part in rotating call for 24-hour coverage of community patients and dedicated palliative beds in local hospital
Clinical nurse specialist	<ul style="list-style-type: none"> ▪ establishes and implements treatment plans for pain and symptom management at home ▪ makes daily home visits independently and with MD ▪ provides clinical support to families and community nurses ▪ facilitates biweekly rounds with the entire team ▪ takes part in monthly rotating call for after hours and weekends
Psychosocial spiritual bereavement clinician	<ul style="list-style-type: none"> ▪ provides emotional and spiritual care for individuals/their families ▪ assesses, acknowledges, and nurtures those living with advanced illness or on the journey of dying regarding all personal, cultural, financial, legal, and spiritual needs ▪ assists in advanced care planning, funeral/memorial service planning ▪ offers grief and bereavement follow-up support

While team members continue to work as part of the regional palliative care program and Stedman Hospice, their activities can be tailored to the needs of the Six Nations program. As of 2015, the Palliative Shared Care Outreach Team was located back to Six Nations. They have completed their training as expert clinicians and gained their credentials as palliative physician, clinical nurse specialist, and master of social work.

2. Development of a Care Pathway for Clients Who Need Palliative Care

A care pathway outlines, in writing and in detail, the anticipated care required by a person, and it places the care in the appropriate sequence and time frame; it is then agreed upon by a multidisciplinary team. The Six Nations Leadership Team, consisting of internal and external healthcare professionals, developed a detailed care pathway to guide the provision of palliative care to its clients. Generally, clients are identified as needing palliative care when their life expectancy is less than one year and when they are having pain and symptom issues. A

benefit of following the care pathway is that care needs of the client and family will not be overlooked.

The care pathway specifies who makes referrals to the team and how they are made. It outlines all of the processes for communication and consent with the clients and between healthcare professionals. It indicates how quickly clients are to be seen based on need, describes the activities of home visits by team members, and describes use of the in-home chart. The pathway includes post-death staff debriefings and bereavement visits to the caregivers. The full care pathway is included in the EOLFN (2015) workbook. Table 2 shows two examples from the care pathway.

Table 2
Examples from the Care Pathway

Initial client contact	The CCAC palliative case manager or the Home and Community Care case manager (whoever receives the referral first) sets up an initial joint home visit. A palliative care assessment is completed and shared between the two case managers, and a consent form is signed for each agency. All appropriate palliative services are initiated and required medical equipment is put in place. Client and family are given the contact information for each service to ensure they can access assistance on a 24/7 basis. The end-of-life care checklist is put in the home, which includes the telephone number for all services, including the funeral home.
End of life	Expected Death in the Home forms are completed and discussed with the client and family by the CCAC palliative case manager, the acute nursing agency, or the palliative physician or clinical nurse specialist. All nurses have been trained in Pronouncement of Expected Death, and the palliative physician completes the death certificate if the family physician is not available. Case managers notify each member of the clinical team that an in-home death is being planned; thus, no calls are made to the emergency response team. Families are encouraged to call the acute nursing provider who notifies the Palliative Shared Care Outreach Team.

The clinical nurse specialist commented on the value of the home visits in an interview with the Six Nations community facilitator:

I think the home visits are the most important. That initial home visit because after that, they know who they're talking to and can connect a face with the person they are talking to on the phone. Also bringing the physician to the home is important.

3. Increased Home Deaths Compared to Hospice or Hospital Deaths

Data were collected on the number of referrals and the location of death. Table 3 shows a 170 percent increase in the number of referrals to the palliative care team over the 3 years it has been operating. Table 4 indicates that home deaths far outnumbered hospital deaths over the 3-year period the team has been operating.

Table 3

Number of Palliative Shared Care Outreach Team Referrals (Six Nations and Surrounding Areas)

Year	Number of Referrals
2012	30
2013	80
2014	81

Table 4

Location of Deaths - Six Nations Palliative Shared Care Outreach Team Clients, 2013–2015

Location	Number of Deaths
Home	55
Hospital	22
Hospice	6

As more people died at home with access to quality palliative care, members of the community were more willing to be referred. The following example of this was provided by the psychosocial spiritual bereavement clinician, who herself benefited from the palliative care program when a family member was dying.

And she referred me to ... the nurse who was on call, and it just worked out that Dr. [name] happened to be in the area and she was in my aunt's home within fifteen minutes. They worked together to make sure that my aunt was peaceful and comfortable in the last days of her life. (Family member of dying Six Nations resident)

4. Access to Palliative Care Education and Mentorship for Local Healthcare Providers

Palliative care education for the local healthcare providers in Six Nations was a critical part of capacity development. In addition to 1 year of mentorship with the Stedman Hospice clinicians, the Six Nations team (physician, nurse, psychosocial spiritual clinician) took a 15-

hour inter-professional course, Learning Essential Approaches to Palliative and End-of-Life Care, offered by Pallium (<http://www.pallium.ca>). Other courses offered were Palliative Care for Front Line Workers in First Nations Communities (<http://www.cerah.lakeheadu.ca>), which is a 15-hour introduction to the philosophy and principles of palliative care, and The Fundamentals of Palliative Care Training and CAPCE (Comprehensive Advanced Palliative Care Education), both offered by the Pain and Symptom Management Program consultant in the Brant, Haldimand, Norfolk region.

Personal support workers, homemakers, social workers, and nurses all benefited from this education. Two team members commented specifically on the benefits to them:

Well, I think my confidence has changed, I feel more assured about what I'm doing.
(Clinical nurse specialist)

Like when I took this job on, my vision was working with our people and our community to develop programs and to meet the needs of our people, and I'm okay being mentored and I accepted that and I respected that, and I really truly appreciate it 'cause I have learned lots. (Psychosocial spiritual bereavement clinician)

The mentorship of team members with Stedman Hospice was a very positive experience that continued for a year. The following, in the words of the Six Nations community facilitator, describes the mentorship experience between the newly hired members of the Six Nations palliative care team and the Stedman Hospice palliative care providers:

One of the core values of the Haudenosaunee is the state of peacefulness, understanding the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. This was the personal relationship that existed between the Stedman Hospice and the Six Nations Home and Community Care Program, that of respect. The hospice was more experienced in dealing with end-of-life care and offered their expertise. In turn, Six Nations would offer its cultural perspective so that palliative Aboriginal clients would have culturally sensitive end-of-life care.

We saw it as a mutually beneficial partnership. Our new palliative care team would gain valuable expertise by working with clients throughout the entire county and dealing with a varied number of issues. The clinical nurse specialist would begin by visiting with the more experienced nurses from the hospice and would then carry her own caseload, which would include all Aboriginal clients. The psychosocial spiritual bereavement clinician would meet with the other psychosocial support clinicians and learn of the practices of other denominations. She would follow clients through their stay in the hospice, attend the day programs and the support groups offered by the hospice.

Throughout the mentorship, the team members would feel the support and be able to consult during regular rounds with the palliative physicians. This partnership would

build and maintain the expertise that would be needed to have a fully functioning Shared Care team.

5. Incorporation of Traditional Teachings to Support Clients and Staff Dealing with Death, Dying, Grief, and Loss

The procedures for Aboriginal clients took consideration of Haudenosaunee teachings and rituals; thus, ceremonies and policies were adapted, such as the medical equipment in the home not being picked up until after the 10-day feast. The community needs assessment clearly showed that the meaning of palliative care for community members may differ from Westernized understandings of palliative care, and that many individuals would need support in understanding and accepting the benefits that a unique palliative care program at Six Nations could offer them.

Throughout their work, palliative care team members were sensitive to individual and cultural wishes as indicated in the following comment:

I have opened my heart more than my heart has ever been opened in my life because I feel that everybody, when you are dying or your loved one is dying, you are in a very vulnerable state and I feel like it's a gift from my Creator to help, help walk with these people and help them hopefully have a peaceful journey. (Psychosocial spiritual bereavement clinician)

The role of the Traditional Knowledge Carrier was very important in supporting clients and families. She was recognized by the community as having knowledge and understanding of the traditional cultural practice of the community, including the language as well as spiritual and social practices, and she worked with people towards the restoration of balance and harmony to the body. The role also included explaining the spiritual transitions to end of life and releasing the loved one. The Traditional Knowledge Carrier worked very closely with the Palliative Care Program and team.

Addressing a gap identified in the needs assessment, a traditional grief and bereavement program was developed by the Leadership Team. The Six Nations community facilitator described this new program:

This initiative brought together family members of clients who received end-of-life care through the SN palliative program. These participants have been on their grief journey for close to a year, and they were to be assisted in their grief with traditional practices and medicines. They attended 10 weekly sessions, which were facilitated by the psychosocial spiritual bereavement clinician and a Traditional Knowledge Carrier. The participants were assisted to understand bereavement and the grief journey, and were presented with traditional teachings with ceremonies and traditional medicines for teas and baths and taught self-care. They were assisted with listening, witnessing, companionship. They were supported and nurtured within a healing sharing circle, and were assisted to realize that we cannot change the past but learn to live in the future. The participants were helped in healing their hurt with sharing of realistic expectations for

grief and mourning and encouraging hope, and by giving honour and respect. Five intended outcomes were sought and they included: reawakening the spirit, holistic balance, teachings of self-care, softening the grief, and healing the heart to carry on.

An additional challenge identified in the needs assessment was the burden of grief and loss carried by the staff working within the palliative care program. Not only did staff develop close worker/client relationships, many of the staff were also family members of their clients. As the palliative care program grew, staff expressed the need for grief support for themselves. The Traditional Knowledge Carrier developed and facilitated a traditional ceremony, called the Four Strings Ceremony, which is described as follows:

*The Four Strings Healing Ceremony begins with a presentation of the traditional teachings surrounding this ceremony, and it will not be described to maintain the sacredness of the teaching. The following are the areas that are dealt with: **The Eyes and Tears**—when someone is in great distress as a result of a death in the family, the eyes are in tears which makes blindness and we are unable to see anything, and the mind is hurt by this. To help and comfort you, we place our fingers on the soft white deer-skin of the fawn and wipe off your tears and remove all your sorrows, and give you encouragement to lift your spirit. You are now able to see your grandchildren, your colleagues, and you will think of your duties to your people, and you will feel and be yourself again as there are many days ahead of you. **The Ears**—when a family loses someone, there is great distress and hearing is lost, the mind is hurt by this and unable to hear people around you because the thoughts are on the great loss in the family. The ears are unplugged with the down of an eagle feather so you may hear more clearly and understand the voices of the people around you. You can continue your duties and your mind will be clear and you will feel good for the days ahead of you. **The Throat**—when a person is in great sorrow, the throat becomes clogged and we are unable to speak or swallow food. It is hard to breathe and this has caused your body to become weak with distress. We unplug your throat by drinking fresh clear water and this gives you comfort and strength. You will forget your sorrow and think only of good things and you will feel good and your mind will be at ease. This will bring you comfort and happiness so that you may continue with your duties for your people for days to come. **The Stomach**—when a person is in great distress as a result of the death of a loved one, this causes a weak mind, the body does not function properly, causes an upset stomach and creates nervous tension, and the body becomes weak. You will take the medicine, which is the strawberry. It will settle your stomach, remove the yellow spots, cleanse you within, give you strength, and protect your spirit. Now you will feel good, be yourself, and you will not feel such great loss. This will comfort you so that you may continue with your duties for the benefit of your people for many days ahead. One then goes home and rests, and takes a cedar or salt bath, and perhaps follows up with a massage, and continues to flush their system and hydrate their bodies. (Traditional Knowledge Carrier)*

6. Creation of the Palliative Care Program Booklet

One of the final steps in the intervention was formalization of the palliative care program through creating a written summary of all of the palliative care initiatives that were now integrated into the Long Term Care/Home and Community Care Program. The Palliative Care Program booklet (Six Nations Palliative Care Leadership Committee, 2015), distributed to healthcare providers and community members, opens with the following mission and vision (p. 4):

Mission Statement

Six Nations Health Services is dedicated to ensuring that each individual is respected and treated as a valued human being by providing, promoting, protecting and advocating holistic health home and community care services for current and future generations of the Six Nations Community.

Vision

To provide compassionate, coordinated, and comprehensive end of life care to individuals living in the community of Six Nations.

The program booklet proceeds to describe the team, care pathway, and the medical, social, spiritual, and cultural services of the program in detail, including case management, physiotherapy, occupational therapy, health advocacy, registered nursing, adult day centre, personal support services, community support services, supportive housing, traditional wellness coordination, Traditional Knowledge Carrier, Six Nations family health team, psychosocial spiritual supports (longhouse, local churches, funeral homes), screening, and training of staff and volunteers.

Members of the Six Nations community also created resources for clients and their families. These include a culturally appropriate grief support resource called *The Ones Left Behind* (Martin & Skye, 2011) and an advanced care planning guide titled *Journey Back Home* (Martin, 2009), which helps clients to document their end-of-life wishes. The diversity in spirituality among community members and the need to support and respect this diversity is acknowledged in these two documents as follows:

It is our intention to support our cultural practices to help individuals achieve a sense of peace and wellbeing while they are preparing for the loss of their loved one. The sacred knowledge shared with you may be different from what you have learned as the variances arise from the family, the Longhouse, the Nations and the Community (Martin & Skye, 2001, p.2).

Journey Back Home (Martin, 2009) was authored by the traditional wellness coordinator and reviewed by Traditional Knowledge Carriers prior to being shared. The guide opens with the following acknowledgement:

On behalf of the Six Nations Long Term Care/Home and Community Care Program, I wish to thank the efforts of Christine Skye [Traditional Knowledge Carrier] and many other people who have shared their knowledge to contribute to the development of the Journey Back Home resource. I also wish to thank our Ancestors for making this resource possible, as it would have never come to be if they did not share and teach their knowledge to others for the future generations. The sacred cultural knowledge within this resource is to help assist our families learn about the journey back home to the Creator. In our state of grief, we recognize that it can be difficult to think or function while we are feeling a great sadness. I hope that this resource will guide and help support the families while they prepare and send their loved ones on their journey. (Traditional wellness coordinator; p. 28)

Overall, the Palliative Care Program booklet and resources represent the achievements of the Leadership Team after many years of work. Members of the palliative care program expressed great pride in seeing the outcome of their work, as illustrated by the comment below:

I definitely think this is an important service to provide to our patients, to people who are in need of palliative care services, whether it is just pain and symptom management or end-of-life planning. It's nice that we are available 24/7; there is always a nurse and a doctor on call. (Clinical nurse specialist)

Limitations

The outcomes of this research (i.e., the design of the palliative care program) are embedded in and emerged through the PAR process and the unique context at Six Nations. Thus, the specific palliative care program described in this article cannot be reproduced in other First Nations communities. Contextual variables such as community size, historical background, physical setting, economic status, infrastructure, cultural beliefs, and isolation will influence how each community can develop its palliative care program. Despite this, the achievements of Six Nations of the Grand River Territory can serve to inspire other First Nations communities to implement their own vision for change in care for people who wish to die at home in the First Nations community. It is the community capacity development approach (process of change) described in this article that is applicable to any First Nations community, and by employing it as described, communities can develop their own culturally appropriate palliative care programs that build on local assets and partnerships.

Discussion

Within the overall EOFLN project, the success of the Six Nations community capacity development is impressive. Many factors contributed to it. The motivation, leadership, and vision of the project's community lead were significant, and she was able to mobilize her community. Six Nations also had excellent community resources to build on; it is a large, urban community, with a strong HCC program that was already providing some palliative care services. HCC had

partnerships that could be enhanced with provincial home care and a hospice. The partnership with the EOLFN research team provided timely support and funding for the community facilitator. And finally, there was opportunity in that the province of Ontario was prioritizing the funding of community-based palliative care. This environmental readiness enabled Six Nations to gain provincial funding for their Palliative Shared Care Outreach Team from their LHIN.

In Six Nations the capacity development process required strong commitment from the Project Advisory Committee and Leadership Team over 5 years. There were challenges to be managed. At times, a sense of apathy deterred participation in the project as some service providers felt that nothing concrete would be achieved. There were many competing priorities that required the attention of Six Nations leadership, and palliative care was not always the top priority. It was sometimes difficult to engage participation by community members because of transportation costs to come to meetings. HCC staff lacked coverage for their work when they took time for palliative care planning and education. Delays in getting authorization from political leadership and ethics boards also posed challenges for conducting research activities.

However, receiving timely and ongoing practical benefits of the project will help the Six Nations community members maintain motivation. Also, a strong community engagement through a Project Advisory Committee, decision maker partners, and community facilitator helps sustain interest. Managing environmental impacts is always part of the community capacity development process. In this case, dedication and hard work by the Project Advisory Committee sustained the initiative.

The experience of Six Nations highlights broader policy issues for other First Nations communities who wish to develop palliative care. The EOLFN project found that accessing human resources and equipment is an ongoing issue; jurisdictional issues represent a barrier to funding. Building a team of qualified First Nations healthcare professionals from the community requires education and training. Later, as more and more people chose to return home to die, there was a need for more personal support workers, more nurses and case managers. However, there is no specific funding allotted for end-of-life care in First Nations communities. Both the provincial and federal governments describe themselves as the *payer of last resort* for providing equipment and medication for palliative care. This means that the family, who are often unable to afford this expense, must assume equipment rental costs. Seeking funding from the Non-Insured Health Benefits (NIHB) program is the only option for clients who have no other health insurance coverage. The NIHB approval process can be too lengthy when dealing with end-of-life care.

The new team and program in Six Nations is a work in progress. There is need for continual revision of the team and program to address emerging issues. For example, a recent experience with a client who had end-stage chronic disease highlighted issues in the service partnerships and identified a need for more staff education on pain and symptom management in chronic disease. Discharge planning with families prior to coming home from hospital is often lacking, resulting in families not knowing what to expect in the provision of end-of-life care at

home. There are also specific risk factors to be managed in the use and storage of narcotics for pain relief in the home setting.

The new Palliative Care Program needs to remain culturally flexible and supportive. In the words of the Six Nations community facilitator:

Each family is unique. They may be traditional and attend the longhouse, or they may be Christian and attend one of the many local churches, or they may be a combination of both. We wanted to accommodate both the traditional Elders/healers and pastors, and coordinate a pastoral team that we could call upon as necessary.

It is also very important to support staff with post-death debriefings and sacred ceremonies, and to offer bereavement leave to avoid staff burnout. Work has begun on a wellness strategy, and individual wellness plans for all staff.

The Six Nations Palliative Care Program represents the integration of two caregiving systems. From within Six Nations, the desire to return to the traditional Haudenosaunee philosophy, along with strong leadership and a vision for change by local healthcare providers, initiated and drove the process. External to the community, the Ontario healthcare system respectfully engaged with Six Nations and provided funding, education, and mentorship to support local capacity development. These two systems shared in a process of community capacity development that has implications as a promising practice at the policy level.

The program development is still in process. The future of the Six Nations Palliative Shared Care Outreach Team is unknown as the LHIN Regional Palliative Plan may include a shift to having hospices as Centres of Excellence for palliative care. While this proposal would fit well into the memorandum of understanding between Six Nations and Stedman Hospice, the team anxiously awaits the final plan. The palliative care team will continue to be funded by the province at the current level; however, the growing number of people who want to die at home has put great stress on Home and Community Care resources. The jurisdictional issue of who pays for providing palliative home care services needs to be addressed by the provincial and federal governments. This research suggests that much can be accomplished through federal and provincial health partnerships.

Conclusion

The Six Nations Palliative Care Program model is an innovative and promising practice grounded in community values and Indigenous culture, and successfully supports people to receive their care and die at home if that is their wish. Support is provided for people with advanced chronic disease who are in the last year of life, and those with a cancer diagnosis. The program is integrated within Six Nations Health Services and was developed over 5 years by a Project Advisory Committee and Leadership Team who worked with internal and external health services partners and research partners at Lakehead University. The Palliative Care Program

focuses on meeting the end-of-life care needs of people and their families in a way that incorporates Haudenosaunee traditions, yet individualizes all clients and honours their beliefs.

The need to develop appropriate palliative care programs for First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal illnesses. Creation of the palliative care team and program at Six Nations was done using community capacity development. The process described is applicable to any First Nation that has the vision, leadership, and motivation to develop its own palliative care program. Each community program will need to evolve with unique features that reflect the local community needs, existing community resources, and partnerships with provincial healthcare services. In the EOLFN research, these outcomes have been shared with other First Nations communities through a workbook of research-informed community capacity development strategies (EOLFN, 2015) that are drawn from the work of all four communities.

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Using Photovoice to Understand Intergenerational Influences on Health and Well-Being in a Southern Labrador Inuit Community

Abstract

This research sought to explore one southern Labrador Inuit community's intergenerational relationships, with a focus on seniors' perspectives and understandings of health and well-being. This knowledge is important for accessing and responding to social and demographic change to ensure a continued ability to provide for future generations. Our research employed a community-based participatory research (CBPR) approach and a qualitative, arts-based methodology, including photovoice. Participants in this study included six seniors and six youth from St. Lewis, Labrador, Canada, who were provided with cameras and were asked to take photographs that represent how their lived experience related to the research questions. Our findings demonstrated that strong relationships between older and younger generations, particularly within families, exist in St. Lewis. We argue that these relationships contribute positively to the overall health and well-being of the community. Little is known about how youth and seniors in Indigenous communities perceive one another and their respective roles in a contemporary context. Our research suggests that learning more about the factors that shape senior–youth interaction and communication in St. Lewis may lead to interventions that will support intergenerational contact and, hence, promote cultural continuity and increase overall well-being. The promotion of cultural continuity and well-being is of particular importance in Indigenous communities, given the disruption of culture due to colonialism and given that Indigenous communities with high levels of cultural continuity are healthier.

Keywords

Intergenerational communication, Inuit health and well-being, Labrador, seniors, elders, community-based participatory research, photovoice, traditional learning, resilience

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Introduction

Indigenous elders traditionally passed on to youth the norms, knowledge, and moral values of the whole society. Traditional learning processes included ceremonies, rituals, demonstration, storytelling, and songs (Ulluwishewa, Kaloko, & Morican, 1997). However, colonialism significantly impacted Indigenous family and community structures in Canada, including the transmission of traditional knowledge (Czyzewski, 2011). Factors such as dispossession from the land, disruption of traditional life-ways, intergenerational trauma, and the long-term effects of the residential school system (Martin-Hill, 2009) have resulted in the erosion of intergenerational closeness, particularly between the oldest and youngest members of these communities (Wexler, 2011). These factors have also contributed to community-level issues such as isolation, substance abuse, and violence (Brave Heart 2003; Kirmayer, Brass, & Tait, 2000; Strickland, Welsh, & Cooper, 2006).

The political and historical experience of Indigenous Peoples in the province of Newfoundland and Labrador (NL) is distinct from that of other places in Canada because there was no legal recognition of Indigeneity for its residents upon Confederation with Canada in 1949 (Grammond, 2014). A “designated communities” system was established after Confederation, which acknowledged northern Labrador communities. However, Inuit living in southern Labrador were not recognized despite similarities in cultural background and life-ways shared with their northern counterparts (Grammond, 2014). Grammond (2014) suggests that as a result, southern Labrador Inuit “were subjected to greater assimilative pressures and their identity was often hidden from outsiders” (p. 495). In 1985, persons of mixed ancestry who chose to reaffirm their Indigenous identity formed the Labrador Métis Nation¹, now the NunatuKavut Community Council (NCC). Martin et al. (2012) note that, “NunatuKavut’s most recent efforts to have their Inuit identity formally recognized by the federal government include a land-claim submission to the federal government” (p. 23). Despite a renewed sense of “pride and interest in their roots” (Kennedy, 2014, pp. 11–12), for many southern Labrador Inuit, social needs and challenges continue to reflect a loss of community connectivity and a growing gap between generations (MacCallum et al., 2010).

Intergenerational programming has been identified as a potential means of addressing

¹ We use the term *southern Inuit* throughout the paper to represent the people living within the NunatuKavut territory. However, the participants in our sample self-identified as Métis.

community problems, including poverty, violence, and isolation (Newman, 2003; VanderVen, 1999). Intergenerational programs bring together different generations within or outside of the family context to participate in planned activities designed to benefit all participants (Larkin, 2004). These activities facilitate interaction, cooperation, and exchange between generations by encouraging the sharing of knowledge, skills, and experiences (Abrams & Giles, 1999; Greengross, 2003; Vernon, 1999). Benefits are far-reaching and include a reduction in negative stereotypes and attitudes, increased knowledge and skills, personal and social development, increased self-esteem, and decreased social isolation (Abrams & Giles, 1999; Kuehne, 1999; Stanton & Tench, 2003). Intergenerational involvement can also improve health and confidence, break down social barriers between generations, foster shared experiences, and build community capacity (Ayala, Hewson, Bray, Jones, & Hartley, 2007; MacCallum et al., 2010). Such effects are particularly important in an Indigenous context because senior-youth relationships support cultural continuity, the social and cultural cohesion within a community (Chandler & Lalonde, 1998). Indigenous communities with high levels of cultural continuity and self-determination have been shown to be healthier (i.e., lower youth suicide rates) (Chandler & Lalonde, 1998).

Our research considered the nature of interaction and communication between Inuit seniors and youth living in St. Lewis, NL. Indigenous communities contain a wealth of traditional knowledge that can inform us about how to access, adapt to, and respond to social and demographic change to ensure a continued ability to provide for future generations. Our research took a broad and creative approach, drawing on social, historical, and cultural understandings of relationships between seniors and youth. The purpose of this research was to explore how intergenerational relationships impact health and well-being in St. Lewis. This paper specifically reports on seniors' perspectives of the nature of intergenerational relationships in their community and utilizes these data to evaluate how such relationships might impact health across generations in St. Lewis. Little is known about how seniors and youth in Indigenous communities perceive one another and their respective roles in a contemporary context. This research addressed a gap in knowledge by focusing on seniors' understandings of intergenerational relationships and the barriers and enablers that influence their ability to communicate and engage with youth.

Southern Labrador Inuit Understandings of Health and Wellness

From an Indigenous perspective, health and well-being are often understood holistically (Adelson, 2005; Bartlett, 2003). Good health is viewed as a state of balance and harmony involving body, mind, emotions, and spirit, and links each person to family, community, and the land (Lavoie, O'Neil, Reading, & Allard, 2008). For southern Labrador Inuit, an intimate connection to the land and environment is imperative in the maintenance of good health (Hanrahan, 2000). Resources from the land and sea provide food, clothing, shelter, and medicine (Hanrahan, 2000). As a result, traditional diets based on hunting, fishing, and berry picking are integral to the idea of health (Martin et al., 2012). Labrador Inuit identify a direct link between processed foods and poor health, whereas food from the land is associated with a healthy community (Hanrahan, 2000). In addition to the well-balanced diet traditional foods can provide,

traditional subsistence activities such as berry picking, fishing, cutting wood, and hunting provide alternatives to more common modern forms of exercise such as jogging or aerobics (Martin et al., 2012).

Good practices related to maintaining personal safety in the geophysical environment also contribute to southern Inuit understandings of health; they see themselves as having the ability to influence their own health and well-being by taking care of themselves in this way (Hanrahan, 2000). Thus, personal responsibility for individual and family well-being is at the forefront of Inuit understandings of health (Hanrahan, 2000). In her research on food and global change in St. Lewis, Martin (2009) found that “food not only protected against nutritional deficiencies, but also reinforced a collective solidarity, fostering emotional and mental health and well-being” (p. 48). Hanrahan (2000) draws on the example of a tradition that the first salmon caught is shared amongst community members. This practice stems from a history of caring and respect for the community and assures that even those who may be too young or too frail to catch fish will be guaranteed a meal. This ongoing tradition also cultivates good relationships among community members (Martin, 2009).

A Community Profile of St. Lewis

St. Lewis, NL, is situated in southeastern Labrador, on the coast of the Atlantic Ocean. The community is within NunatuKavut territory, an Inuit-settled area, currently home to Inuit, mixed-Inuit, and European descendants (Martin, 2011). The 2011 census states that St. Lewis had a population of 210 people. Of those, 145 identified as Métis and 15 identified as Inuit (Statistics Canada, 2013), including 85 individuals aged 0–24, 55 individuals aged 25–49, 80 individuals aged 50–84, and no one over age 85 (Statistics Canada, 2013). St. Lewis has an all-grade school (kindergarten to Grade 12) with 33 students. The school has a gymnasium and library where community meetings, after-school activities, social gatherings, as well as senior and youth events are held (Martin, 2009). Additionally, there is a church, health centre, airstrip, and three small stores. Many people in town have an Internet connection; however, there is no cellular phone service. St. Lewis was first connected by road to the Trans-Labrador Highway in 2002, which provided residents with increased access to goods and allowed easier entry into and exit from the community (Martin, 2009).

Historically, St. Lewis relied heavily on the seasonal employment of local cod fisheries; however, with the recent decline of this industry, residents of St. Lewis have been forced to search elsewhere for stable employment (Hanrahan, 2008; Martin, 2011). That search often leads to employment through offshore fishing, which, although more stable, requires workers to leave their homes for weeks or months at a time. There is a direct correlation between the decline in the cod fishery and the decline in the population of St. Lewis, which dropped 28% between 1986 and 2006 because many families could not secure local employment. The population declined by an additional 18% between 2006 and 2011 (Graham, Hussey, Small & Hollett, 2014). The outmigration of younger people in search of employment has led to a demographic shift in the community. While St. Lewis remains a vibrant community today, where cultural traditions have

been maintained, the colonial legacy has impacted community well-being, including senior–youth relationships.

Methods

Canadian Indigenous people integrate knowledge and practices of Western and traditional worldviews as they negotiate their health and well-being (Graham & Stamler, 2010). Conducting research in Indigenous communities thus requires the use of a research approach that can accommodate both. Our research was grounded in a *community-based participatory research (CBPR)* approach in which we attempted to blend Labrador Inuit knowledge with academic theory and expertise. CBPR creates bridges between communities and researchers through the use of shared knowledge and experiences, and it facilitates the establishment of mutual trust that enhances the quantity and quality of data collected. The key benefit of these collaborations is deeper understanding of a community's unique circumstances, and a more accurate framework for adapting best practices to suit the community's needs. In our research, particular attention was paid to supporting an ongoing effort to integrate both community and researcher perspectives in all stages of the research process. This process included developing relationships with community members and disseminating findings back to the community. In particular, we consulted regularly with our community research assistant about the content of our interview guide, the sharing circle format, and our analytic process. Methodologically and analytically, we followed knowledge pathways articulated and experienced by seniors and youth through visual and oral storytelling and a sharing circle. Western methods included semi-structured interviews.

We utilized photovoice, a qualitative, arts-based methodology in which participants are provided with cameras and asked to take photographs to represent how their lived experience relates to the research questions (Poudrier & Thomas-MacLean, 2009; Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). The goals of photovoice are to (a) enable participants to record strengths and concerns in their community, (b) facilitate dialogue about community issues, and (c) make research visible to policymakers (Wang & Burris, 1994). Photovoice is ideal for research with Indigenous communities because it fosters trust, gives community members ownership over research data, and shifts the balance of power to community members; it is consistent with a CBPR approach (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Fals Borda & Rahman, 1991; Minkler, 2004; Minkler & Wallerstein, 2003; Reason & Bradbury, 2001). Photovoice also builds capacity among research participants relating to photography skills and the research process (Castleden et al., 2008; Corbie-Smith, Moody-Ayers, & Thrasher, 2004) and creates a natural opportunity for knowledge mobilization.

Our sample consisted of 10 individuals from St. Lewis, NL. Five participants were seniors² aged 50-75, and five were youth aged 8-24. Because this paper focuses on identifying and addressing seniors' understandings of intergenerational relationships, only senior

² Age 50 and up is often used to define seniors in Indigenous contexts; the impacts of poor health in this population contribute to functional decline at a younger age than in the mainstream population (Reading, 1999).

perspectives will be discussed.³

Our research was carried out in four stages:

1. An information and training session for prospective participants
2. A participant photography assignment
3. Individual interviews with senior and youth participants
4. A sharing circle

Participants were recruited by a local research assistant and invited to participate in the information and training session. At this session, we introduced the project to participants and discussed ethical considerations related to photography and photovoice. Participants were given one week to consider the research questions and take 5 to 10 photographs that represented their understanding of how these questions impacted their community.

Once individuals completed the photography assignment, a follow-up interview was scheduled. Interviews were semi-structured conversations about the content and meaning of participants' photographs. Interviews were loosely structured around the SHOWED approach developed by Wang et al. (2004). Our slightly modified version asked participants to think about each photograph in terms of five structured questions: What do you **See** here? What is really **H**appening here? How does this relate to **O**ur life? **W**hy does this situation, concern, or strength exist in your community? Who could the image **E**ducate? What can we **D**o about it?

Once all individual interviews were completed, we held a potluck supper as a way for participants to gather and tell their stories. Coming together around a meal to share stories was an approach encouraged by our participants and helped to facilitate discussions and ensure equitable opportunities for individual participation (Baskin, 2010). During this event, seniors and youth viewed one another's photographs, discussed the similarities and differences in their photographs, reflected on shared experiences, and thought about future opportunities for meaningful interaction between the two groups. This format was chosen as an opportunity to gather more data as well as an intervention that brought seniors and youth together in a shared, meaningful, and positive setting designed to strengthen their relationships.

During a sharing circle (Figure 1), we used a reflexive process that enabled the group to contemplate the meaning of their photographs. We asked them to identify positive traits of seniors/youth as well as things they would like to learn from or know about the other age group in their community. These discussions were facilitated by the use of cue cards and flip charts to help participants share and record their ideas. Cue cards were used for participants to write down their answers to targeted questions about their interactions with seniors/youth in their community.

As the sharing circle progressed, relationships between the content categories were identified and combined to form themes. Throughout this analytic process, group members identified photographs they believed best represented their community's intergenerational

³ We chose to focus solely on seniors' perspectives in this article because Canadian researchers and policymakers have paid limited attention to the healthcare needs of Indigenous seniors. However, we believe youth and senior perspectives are significant and will highlight and discuss both in targeted publications.

relationships. Additionally, interview transcripts were analyzed and coded by the research team. Thematic analysis was used to identify themes specific to particular generations as well as overarching themes that cut across all age groups.



Figure 1. Seniors and youth engage in the analytic process at the sharing circle.

Relationships

At the outset of the research, the NCC was consulted regarding the appropriateness of this research topic for communities in their jurisdiction. The NCC acts as a gatekeeper to southern Labrador research, and advised the researchers that St. Lewis would be a suitable community in which to conduct the research. We sought support from the NCC for the proposed research and underwent their research review process. Ethical approval was also secured from McMaster University Research Ethics Board. We are currently working with research participants and our local research assistant to design a photo exhibit in spring 2016, which will mobilize knowledge back to the entire community. Written reports for the NCC and St. Lewis have also been prepared.

Results

Three major interrelated categories emerged from our analysis: Connections to Family; Teaching and Storytelling; and Traditional Lifestyles, Heritage, and Values. These categories are described below.

Connections to Family

Senior participants spoke warmly of their relationships with youth in the community, particularly their grandchildren. The importance of family was a key theme that emerged in seniors' photographs and interviews. Grandparent–grandchild relationships appear to be very strong in this community, based on participants' stories. All senior participants told stories about their grandchildren or their relationships with their own grandparents.

In St. Lewis, youth often start families in their early twenties, with the result that as many as five generations may be alive at the same time. Two participants in our sample discussed having the opportunity to take a “five generations” photograph. As a result, it is common for cross-generational relationships to extend beyond grandparents and grandchildren to great-great-grandparent and great-great-grandchild.

So we got fifth-generation picture ... I said okay, before you leave, I want the picture of my grandfather, my mother, me, my son, and my granddaughters. And all of us were the oldest in the family. (Senior01)

Describing her photo, another participant spoke with great emotion about how meaningful it was to her that her granddaughter brought her great-grandson over to her house to visit and described the special bond they had developed as she taught him to make pancakes.

This is the story right here in that picture. This is my little great-grandson, and he and I got a thing. When he first started coming here, like after he got old enough, he was here one day and I said, “What are we going to feed you? Why don't we try and make some pancakes?” “Ok, Nan,” he said, “me help.” I said, “Yes, you help.” And when he come now, he always first thing says, “Cakes, Nan?” And that's OUR thing [said with pride]. That's our thing, and this is what you want to show your children, little things like this. (Senior02)

The pride expressed among seniors about their relationships with their children and grandchildren indicated that these relationships contribute positively to seniors' mental and emotional well-being. Visits with the young people reduce social isolation, provide opportunities for seniors to pass on their knowledge and skills, and allow seniors to learn about younger generations' perspectives of the world.

Although seniors lamented that changes in technology and ways of life were potentially negatively impacting intergenerational relationships, some seniors described positive changes to grandparent – grandchild relationships that had occurred in their lifetime.

I think seniors and youth seem to be closer than when we were [young]—I remember when we were growing up my grandmother didn't participate in our lives like they do now. Grandmothers babysit their grandchildren and when we were younger, you'd go visit grandmother at Christmas, we'd visit her probably a few times a year ... and when she spoke, you listened.

And now I think they are closer now to their grandchildren. And I think youth and seniors interact better now than they did back then. (Senior03)

This participant described that in her youth, meetings with her grandmother were reserved for formal occasions, and she was not close with her grandparents. By contrast, she described her relationships with her grandchildren as close and centered on shared experiences, day-to-day interaction, and fun. Another participant spoke similarly of the changes to grandparent and grandchild roles. She described being sent to take full-time care of her ailing grandmother at age eight and emphatically expressed that she would never ask a child that young to take on such a role today.

Grandchildren are a constant presence in many seniors' lives in St. Lewis today. Although many families are separated by large geographical distances, photographs of grandchildren were featured prominently in all of the seniors' homes and were a recurring theme in their photovoice assignments.

Teaching and Storytelling

All participants mentioned teaching, knowledge sharing, and storytelling either directly or indirectly. Seniors expressed their desire for youth to have a better understanding of the value of work and what it was like for them growing up. One of the key ways in which senior–youth relationships contribute to community well-being is through the transmission of knowledge about the land and traditional food procurement activities. Teaching was important to these seniors. They recognized that they have knowledge that will potentially be lost if they do not pass it on to younger generations. Rapid changes in the last several decades—an increasingly sedentary lifestyle, increased community accessibility with the building of a road, increased access to non-wild food, and changing technology—have decreased the necessity of traditional knowledge and skills for survival. Yet, for these senior participants, passing on this knowledge and ensuring the continuation of certain skills was a matter of pride. Seniors said they wanted youth to understand where they came from and to maintain the skills that allow them to sustain themselves. Seniors repeatedly expressed the importance of youth having knowledge of basic skills such as cooking, sewing, and fishing.

Seniors expressed a great deal of pride in traditional activities. In the spring, they look forward to ice fishing and seal harvesting. Summer and fall bring duck hunting and berry picking, and with winter comes wood-cutting and hunting. Seniors also described knowledge and skills necessary for carrying out these activities, such as boat building, snowshoe making, winter survival, and setting fishing nets. Although many of these skills remain in the community, knowledge of some techniques is held by fewer people than in the past.

From our participants' descriptions and observations in the community, it is clear that traditional skills are in many cases passed on to youth by their grandparents and great-grandparents rather than their parents. These skills were less necessary for survival among younger people than for older generations. As a result, some people in this middle generation are not as skilled in these activities or as able to pass them on. Regardless, older people in the community have a strong desire to see these traditions and knowledge continue.

It means a whole lot to me to be able to carry on with tradition 'cause I knows my grandchildren is never going to learn how to set a cod trap, they're never going to learn how to set a gill net, and that was a way of life for us. (Senior02)



Figure 2. Grandchildren helping grandfather to pull a boat out of the shed.

Teaching and storytelling were seen as important, and the particular knowledge and skills that were taught emerged as their own theme as many of these were closely tied to traditional lifestyles and skills (sewing, crafts, cooking). Knowledge transmission through teaching and storytelling was common within families but also occurred in the broader community. For instance, seniors gave presentations in school classes about heritage and traditional skills such as snowshoe and slipper making.

Teaching and learning were understood to be reciprocal. Many senior participants expressed an interest in learning from youth in the community, and youth were perceived to play a valuable role in teaching seniors about technology and the “new way of life.”

I see the roles of elders and youth in our communities as interconnected and also individualized, which helps to balance out our community. Elders give us wisdom and stories, a past that we are trying to hold on to, traditions and culture. Our youth are the energy of the community, they are the ones that we are passing our wisdom, cultures, stories, traditions

on to. In turn they are adding their own style of life and intertwining it with the old style. (Senior04)

Additionally, many seniors we spoke with were relatively young (age 50), and they expressed their continued enjoyment of learning from *their* elders.

Traditional Lifestyles, Heritage, and Values

Sharing knowledge about traditional ways of life, heritage, and values was important to senior participants. Engaging in traditional activities that reflect subsistence practices and crafting emerged as an important example of situations where seniors and youth came together, with positive potential benefits for health.

I tell you about my father helping with the snowshoes. When [my son] was probably 10 or 12, I think, they had Dad do a class with his age group to show them how to do snowshoes. Dad is 75 now, so that was a few years back, but like every year there is somebody trying to keep that up. 'Cause like they had slipper [making], they showed them how to do slippers this spring. Those techniques and everything that we learned as youngsters, they are being passed on to younger generations to keep. (Senior01)

I'd like the kids to remember their heritage, the way we grew up. I don't want them to lose that. (Senior03)



Figure 3. St. Lewis Heritage Society Museum.

All participants expressed a great deal of pride in their community and the natural environment in which they live. A majority of their photographs depicted favourite places on the landscape such as family fishing spots and cabins. Community pride was strong among the seniors, and it was clear that they valued the maintenance of this pride and wanted to ensure that youth felt the same way about their history and community. Seniors benefited by sharing their pride with the youth and by being engaged in the community. For example, one senior spoke about senior–youth outings involving boating, hunting, fishing, and berry picking:

Like last fall they took them out in the boat and showed them how to duck hunt, and cod fishing and berry picking ... in the fall they go berry picking for the day, they'll come back, they'll make those berries into jam and they bring it to the seniors' home in Mary's Harbour. (Senior04)

This example illustrates the potential benefits of interaction across several generations. Seniors had the opportunity to transmit knowledge and skills to younger generations and youth had the opportunity to be able to engage with an older generation of seniors and provide them with the fish and berries that they harvested. As one participant expressed, this type of activity is “great, 'cause everybody benefits” (Senior04). Similarly, participants shared the value of an event held at the school for Grandparents' Day where grandparents have the opportunity to go into the school and share stories and skills (e.g., making snowshoes, rug hooking) with youth. During the sharing circle, one senior expressed her belief that there “should be more opportunities for that because both parties [seniors and youth] can get a lot out of it” (Senior05).

One participant who took a photo of blackberries explained that growing up she “practically lived off the land” and her mom taught her how to make blackberry pudding, which they made every Sunday for dinner (Senior05). Serving this pudding to her family and friends is a continuing tradition in her family. While picking blackberries is a form of cultural continuity that allows this participant to feed her family and remain active, she said youth today do not like picking berries, which she said “breaks me heart” (Senior05).

Limitations

The findings of this research are limited by data that comes from a single, small community of Inuit and Métis people in NL. A further limitation is that our sample of seniors was relatively young, the majority between age 50 and 60. Thus our results may not be generalizable to a population of older seniors from other communities and do not fully represent the heterogeneity of experience. Additionally, all senior participants were women. We recognize that our research and analysis would have been more balanced if we had included senior men's perspectives; however, given the constraints mentioned above and our reliance on others to facilitate the recruitment process, this was not feasible.

Discussion

Our findings relating to senior–youth relationships in St. Lewis, NL, reveal that older generations feel they have strong relationships with youth, particularly within their families. We posit that these relationships contribute positively to the overall health and well-being of the St. Lewis community in several ways. Here, we focus on the benefits to seniors' well-being.

Themes emerging from this research are closely interrelated and include: the importance of family, pride in their community, connection to the natural environment, teaching, storytelling, and traditional knowledge and ways of life. Although seniors spoke only peripherally about the health benefits of their interactions with youth, it is clear that there are many positive outcomes resulting from intergenerational relationships. For example, connecting with youth through arts, crafts, music, and community contributes to social participation and engagement among St. Lewis seniors. This type of social engagement has been demonstrated to have positive health outcomes for older adults including: reduced disability, mortality, and depression, and increased cognitive functioning and self-rated health (Richard, Gauvin, Gosselin, & Laforest, 2009). Additionally, community involvement contributes to empowerment, which is closely connected to health (Richard et al., 2009). Involvement with the community provides an opportunity for seniors to pass on cultural knowledge and traditions to youth, which is an important component of cultural continuity. Furthermore, when seniors share teachings and stories with youth, opportunities for engagement are enhanced (Lewis, 2011). It was clear that senior participants were enjoying the benefits of this type of interaction.

Participants described how living in Labrador, specifically St. Lewis, is connected to a sense of identity and belonging, and that this place possesses nurturing qualities. They described how traditional activities such as hunting, fishing, wood-cutting, boating, and berry picking build group cohesiveness and a sense of empowerment, particularly among seniors and youth. These observations are consistent with other literature, which suggests that participation in cultural activities leads to better health and wellness in Indigenous communities (Dockery, 2010). Although this literature often focuses on the benefits for youth, it is clear from our findings that there are comparable benefits for older people.

Participation in sports and physical activity, as well as healthy eating through traditional food procurement, are important and much desirable in St. Lewis. In fact, seniors emphasized their responsibility to show young people how to live off the land, preparing food, eating healthy foods, and being physically active. Engagement in these activities also provides additional opportunities for older people to share stories and experiences with youth. Greenwood and de Leeuw (2007) suggest story is essential in the transmission of knowledge, and that “this can be learned from the land and from the connections with the land, and from the stories that elders tell us about the land and our relationship to it” (p. 53). Our research supports the idea that time spent engaging with youth in these activities is beneficial to health and well-being.

Our results also demonstrate that seniors desire to be role models and mentors for youth, teaching traditional cultural values and practices that support resilience, health, and well-being. Our research acknowledges that determinants such as culture and social support can lead to

greater resilience and positive development in youth, but that it is similarly important to consider how such determinants can benefit older people.

Conclusion

Through this research, we gained insight into the interactions between Indigenous seniors and youth, and determined how senior–youth relationships contribute to the health and well-being of St. Lewis community members. Seniors in St. Lewis have vastly different life experiences than youth due to significant changes in the economy and accessibility of the community in recent decades. However, their eagerness for interaction with youth was evident. From the perspective of seniors, benefits of this interaction included the reinforcement of their meaningful, traditional roles as teachers, mentors, storytellers, and knowledge keepers. Furthermore, our research suggests that learning more about the factors shaping senior–youth interaction can lead to interventions that support intergenerational contact and, hence, promote cultural continuity and increase overall well-being. These findings also have the potential to lead to future initiatives that support senior–youth interactions in St. Lewis. Programming that engages seniors and youth could contribute to community resilience in creative, innovative, culturally specific, and historically sensitive ways. Addressing these issues has the potential to improve quality of life in St. Lewis across many generations. Photovoice contributed additional richness to the data and also led to a tangible outcome (photos) that can be a valuable part of the knowledge mobilization process. The photovoice process acted as an intervention bringing seniors and youth together in a productive, shared endeavour that can help bridge the gap between these groups and may lead to future interventions or collaborations.

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The Eight *Ujarait* (Rocks) Model: Supporting Inuit Adolescent Mental Health With an Intervention Model Based on Inuit Knowledge and Ways of Knowing

Abstract

Objective: This study responded to a community-identified need to form an evidence base for interventions to promote mental health and wellness among youth in Nunavut. **Methods:** A literature review was conducted using the terms *adolescence* and *Inuit* and *intervention* or *program* or *camp* or *land-based*. PubMed and Google Scholar databases were used to find peer-reviewed and grey literature on community-based youth programs. The literature review was presented to parents, elders, and youth for discussion over several months in 2009-2010. **Results:** Key themes included: self-esteem, physical activity, stress and coping, positive peer relationships, Inuit identity, mental health and well-being, and the effects of intergenerational trauma on youth in Nunavut. Themes were incorporated into a model for youth mental health interventions based on Inuit terminology, philosophy, and societal values—the Eight *Ujarait*/Rocks Model. The model was implemented as a camp program in 6 pilots in 5 communities from 2011 to 2013. Data were collected before and after the camp. Results indicated that the program fostered physical, mental, emotional, and spiritual wellness among youth. Parent observations of participants included an improvement in behaviour and attitude, strong cultural pride, greater confidence in identity, and improved family and community relationships. **Conclusion:** Evidence-based, community-driven models for youth mental health interventions in the North hold promise. The application of one such model through a camp program had a lasting impact on the individuals involved, beyond their immediate participation. Long-term monitoring of the participants, and ongoing evaluations of camps as they continue to unfold across Nunavut, are needed to contribute to the robust evidence base for this program over time.

Keywords

Inuit, youth, adolescents, mental health, evidence-based, holistic, land-based interventions, public health, Indigenous

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Introduction

Mental health and wellness is one of the most pressing issues identified by community members and organizations in Nunavut today (Ajunnginiq Centre, 2006; Healey, 2007; Hicks, 2007; Kirmayer, Tait, & Simpson, 2009; Nunavut Tunngavik, 2011; Tierney, 2007). In the 2007–2008 Inuit Health Survey, 48% of respondents reported having thought seriously about suicide at some point in their lives, and 14% of respondents reported recent suicidal ideation (Galloway & Saudny, 2012). Rates of attempted suicide in Nunavut are extremely high. Twenty-nine percent of respondents reported a nonfatal suicide attempt at some point in their lives, and 5% of all Nunavut respondents reported a recent nonfatal suicide attempt (Galloway & Saudny, 2012). Younger Nunavut adults (18–49 years) reported more recent suicide attempts than older people. Reports of suicidal thoughts and suicide attempts were more common among women than men (Galloway & Saudny, 2012).

In 2011, 50% of Nunavut's population were under the age of 24 (Nunavut Bureau of Statistics, 2011). The large, growing population of youth, and concerns about the mental health of young Nunavummiut¹, prompted a series of studies and public engagement sessions about

¹ *Nunavummiut* is the Inuktitut term for the people of Nunavut.

mental health programs and services in 2009 and 2010 (Mearns, 2013; Nunavut Tunngavik, 2011; Qaujigiartiit Health Research Centre, 2010a, 2010b, 2012a, 2012b). One of the most pressing concerns identified by community members in these public engagement sessions was the need for youth programs that would demonstrate positive outcomes for the participants. In this paper, we will describe key aspects of one initiative led by the Qaujigiartiit Health Research Centre in Iqaluit, Nunavut, which was to develop a model for youth wellness interventions based on Inuit and community perspectives on adolescent well-being. This model was named “The Eight *Ujarait*/Rocks Model for Youth Wellness Interventions.”

Background

Nearly three centuries ago, the arrival of European whalers and explorers to the Canadian Arctic marked a significant turning point in the health of Inuit. Interaction with European visitors through trade and gift exchange resulted in the introduction of infectious diseases that quickly took their toll among the Inuit population. During the 1920s, 1930s, and 1940s, tuberculosis, influenza, and sexually transmitted infections repeatedly ravaged Inuit populations (Inuit Tapiriit Kanatami, 2005; Sandiford Grygier, 1994; Waldram, Herring, & Young, 2007), and many of the same illnesses continue to present in high numbers in northern communities today (Healey, 2014a; Nunavut Department of Health & Social Services, 2012; Orr, 2013). Since then, Canadian Inuit have experienced a cultural shift from a nomadic, subsistence lifestyle to working and living in communities year-round (Inuit Tapiriit Kanatami, 2005). Although the process of relocation to communities began as a response by Indigenous Peoples to the presence of fur traders, explorers, and missionaries, it took new form with the systematic efforts of the government in the 1950s to “resettle” Canada’s North (Tester & Kulchyski, 1994). As a result, Inuit were relocated to southern Canada to cut relief costs; to remote High Arctic regions to maintain Canadian sovereignty and support the economic initiatives of the Hudson’s Bay Company; and off the land and into settlements to facilitate the provision of supplies, education, and medical care (Royal Commission on Aboriginal Peoples, 1996; Qikiqtani Inuit Association, 2010). In 1951, the first government-regulated school for Inuit was opened in Chesterfield Inlet (Pauktuutit, 2007). For some communities, up to three generations of Inuit children were sent away from their families to attend day schools in the larger communities (Pauktuutit, 2007). Residential schools for Inuit continued to open into the 1960s, and by 1963, 3,997 Inuit children were attending these schools (King, 2006). In June 1964, 75% of 6- to 15-year-old Inuit children and youth were enrolled in the schools (King, 2006). These students are the parents and grandparents, uncles and aunts of today. The experiences of resettled Inuit continue to have an impact on many Nunavut residents to this day (Healey, 2014a; Kral, Idlout, Minore, Dyck, & Kirmayer, 2011; see also the 12 short films at www.iqqaumavara.com).

Trauma experienced during and after the settlement and resettlement era in the eastern Arctic (Healey, 2015; Kirmayer et al., 2009), and the loss of accumulated Inuit wisdom, knowledge, teachings, and practices that occurred as a result (Condon, 1990; Mancini Billson & Mancini, 2007; Moffitt, 2004; Qikiqtani Inuit Association, 2010; Steenbeek, Tyndall,

Rothenberg, & Sheps, 2006), are factors contributing to the mental health challenges in today's communities. Previous research has indicated that many young Inuit today do not feel a connection to or sense of stewardship for the land (*avatittinik kamatsiarniq*), or knowledge of harvesting skills and practices that are highly regarded in Inuit society (Nunavut Tunngavik, 2011; Searles, 2010).

Defining well-being. Well-being is an all-encompassing and holistic concept. Well-being affects every part of our daily lives, and how well we feel every day plays a major role in our health and how we get along with others or react to events. In this paper, we are discussing well-being in terms of an interactive process of becoming aware of and practicing behaviours that contribute to a sense of social, spiritual, physical, intellectual, and emotional balance. In a discussion document prepared by the Assembly of First Nations for the Mental Health Working Group, mental wellness was defined as “a life-long journey to achieve wellness and balance of the body, mind and spirit ... [and] includes self-esteem, personal dignity, cultural identity and connectedness in the presence of a harmonious physical, emotional, mental and spiritual wellness” (Mental Health Working Group, 2002).

In an analysis of positive mental health and mental health problems among Canadians, Stephens, Dulberg, and Joubert (1999) provide evidence linking current stress, social support, life events, education, and childhood traumas to several indicators of both positive and negative mental well-being. The authors define mental well-being as having the ability to cope effectively with challenges to both mental and physical functioning. Such abilities or attributes include happiness, satisfaction, self-esteem, mastery, and a sense of “coherence” (Stephens et al., 1999). In the context of Nunavut's colonial history and the prevalence of a number of issues, including violence, sexual trauma, substance use, suicide, and the sense of grief expressed by those who feel the loss of Inuit identity, achieving a sense of well-being can be a daily struggle.

Methods

This study was conducted by the Qaujigiartiit Health Research Centre, an independent community research centre that was formed by Nunavummiut to use research as a tool for action on community-identified health priorities. Two of the authors of this paper are from Nunavut and were considered older youth at the time of the development of this study, and their life experiences, perspectives, and community relationships informed much of the direction and motivation behind the study. The third author was also a Nunavut resident whose children and partner are from Iqaluit, and was embedded in her community, carrying with her a deep respect and understanding for Inuit ways of knowing and doing.

The study followed an Indigenous research framework based on Inuit philosophy called the *Piliriqatigiiniiq* Partnership Model for Community Health Research (Healey, 2014a). The study was registered with the Nunavut Research Institute according to the protocols that exist in Nunavut.

First, a review of the literature was conducted, using the terms *adolescence* and *Inuit* and *intervention* or *program* or *camp* or *land-based*. PubMed and Google Scholar databases were used to find peer-reviewed and grey literature. In the grey literature, books and reports on community-based youth programs were identified. Literature was synthesized and examined for thematic topics, with particular focus on youth program design, primary topic of focus for the program, and program attributes that contributed to successful implementation.

Second, themes from the literature review were presented to community members, parents, elders, youth, and youth workers for comment in a series of community consultations/open dialogue sessions in Nunavut between 2009 and 2010. These sessions followed a consensus-based method similar to that outlined by Chatwood et al. (2015). The 37 participants were from Iqaluit, Panniqtuuq, Iqalututtiaq (Cambridge Bay), and Qurluqtuq (Kugluktuk). They were asked to comment on the aspects of youth programs they felt were strengths, with particular emphasis on the skills and values youth should have the opportunity to learn while participating in such programs. Consensus on core concepts was achieved through an ongoing process of discussion and revision. The information shared by community members echoed the suggestions in the literature for community-driven, culturally relevant program models for Indigenous youth. Core concepts from the literature and community dialogue sessions were incorporated into a model for wellness interventions focusing on Nunavut youth, as presented here. The model was developed by the authors and validated by a subset of community members from the open dialogues who agreed to be contacted again for this purpose.

Third, the model was piloted as a camp program to validate the core concepts of the model. The model was implemented in a series of youth camps delivered six times in five communities in Nunavut between 2011 and 2013. The five communities were Panniqtuuq, Coral Harbour, Cambridge Bay, Arviat, and Iqaluit. Each camp ran for 2 weeks. Forty-eight youth participants, eight youth peer leaders, and 15 facilitators participated in the camps. Data were collected from campers and parents via an interviewer-administered questionnaire before and after participation in each camp. Findings are presented and discussed.

Results

The findings are presented in three sections: (a) the literature review and consultations, (b) the Eight *Ujarait*/Rocks Model, and (c) early results of model implementation.

Literature Review and Consultations

Themes emerging from the literature, which were validated and discussed in the open dialogue sessions/consultations with community members, included development of adolescent identity, Inuit cultural identity and practices, positive peer relationships, physical activity and mindfulness, stress, mentorship, coping skills, and self-esteem.

Development of adolescent identity. The community dialogues identified the diverse needs of adolescents and identity development as core elements for a youth program. The World

Health Organization (2016) defines adolescence as the period of time between the ages of 10 and 19 years. Adolescence is a period marked by rapid physical and behavioural changes. The physiological developments occurring during adolescence are triggered by a pre-set biological mechanism for growth and change (Steinberg & Sheffield Morris, 2001). This period of development is viewed as a time for self-exploration and identity formation (Steinberg & Sheffield Morris, 2001). From the perspective of Inuit elders, adolescence is viewed as a critical time for learning about decision-making, discovering new interests and talents, establishing some independence, demonstrating capabilities, preparing for the future, identifying with social groups, showing love, contributing to the community, and *pilimmaksarniq* (developing skills through effort and practice; Qaujigiartiit Health Research Centre, 2015; Kral, Salusky, Inuksuk, Angutimarik, & Tulugardjuk, 2014). Similarly, in a review of major developmental and personality theories, Vleioras and Bosma (2005) highlighted the following concepts in the development of adolescent identity: holding a positive opinion about oneself (self-acceptance); being able to choose or create contexts appropriate for one's psychological condition (environmental mastery); having warm and trusting relationships and being able to love (positive relations with others); having goals, intentions, and a sense of direction (purpose in life); continuous development of one's potential (personal growth); being self-determined and independent (autonomy).

Exposure to caring adults and positive social connections has been shown to encourage self-examination and knowledge seeking about the self (Vleioras & Bosma, 2005). Such connections are also important in the relational worldview of Inuit and other Indigenous Peoples with kinship-based societies (Thayer-Bacon, 2003). Adolescents require the opportunity to develop supportive relationships with adults and role models who can be resources for them in the community, including their immediate and extended family (Qaujigiartiit Health Research Centre, 2014). Membership within a social or cultural group also has been shown to promote protective factors for adolescent mental health, including continued self-exploration and commitment to a consistent identity (Dien, 2000; Klimstra, Hale, & Raaijmakers, 2010; Lachman, 2004; Steinberg & Sheffield Morris, 2001; Vleioras & Bosma, 2005).

Inuit cultural identity and practices. Various studies support land-based programs and the incorporation of time on the land for healing and reconnecting with one's Indigenous heritage (Ilisaqsivik, 2010a, 2010b; Searles, 2010; Takano, 2005; Tierney, 2007; Wilson, 2003). Many Indigenous groups in Canada have been reclaiming traditional practices, relearning land and hunting skills, and revitalizing Indigenous languages in the wake of the colonial experience (Corntassel, Chaw-win-is, & T'lakwadzi, 2009; Pauktuutit, 2012; Qikiqtani Inuit Association, 2010; Truth and Reconciliation Commission of Canada, 2012). Time on the land has been incorporated into healing programs for adults and youth struggling with substance misuse, trauma, incarceration, and the effects of collective/intergenerational trauma (Berman, 2009; Brady, 1995; Dorais, 2005; Lyons, 2010; Robbins & Dewar, 2011; Searles, 2001, 2010). The power *nuna* (land) holds for Nunavummiut is enriching and healing.

In today's increasingly globalized society, access to information, media, and Western pop and youth culture have been identified as contributing to a perceived divide between young Inuit and their elders or knowledge holders (Condon, 1987; Healey, 2014b). Possessing a strong cultural identity is known to increase self-esteem, self-confidence, and life purpose (Martinez & Dukes, 1997), and it was a prominent, overarching theme in the review and community dialogues.

Positive peer relationships. Friendship and a sense of belonging in early and late adolescence are among the most important aspects of a young person's life. Developmental theorists, sociologists, psychologists, and personality experts describe peer relationships during adolescence as influencing self-esteem (Erikson, 1968; Waldrip, Malcolm, & Jensen-Campbell, 2008), academic competence (Vaquera & Kao, 2006), involvement in sports teams/activities (Roseth, Johnson, & Johnson, 2008), psychological health (Steinhausen & Metzke, 2001), and purpose in life (Allen, Porter, McFarland, Marsh, & McElhaney, 2005; Daniels & Campbell, 2006; Wilkinson, 2008). At the same time, the added pressures that accompany popularity can lead some youth to engage in risk-taking behaviours if their peers do not value academic achievement, sports involvement, or other social behaviours (Allen et al., 2005; Parker, Rubin, Erath, Wojslawowicz, & Buskirk, 2006). Setting the tone for peer acceptance and respect, and structuring the Eight *Ujarait*/Rocks Model around positive behaviours, is at the core of this youth intervention. The promotion of peer acceptance and reciprocal support can be demonstrated throughout the learning modules and participatory activities.

Physical activity and mindfulness. The positive benefits of exercise for physical and mental health are well known (Dunton, Whalen, Jamner, & Floro, 2007; Janssen & LeBlanc, 2010; Lavallée, 2007). Physical activity contributes to improvements in youth academic performance and mental health indicators (Daniels & Campbell, 2006; Hillman, Erickson, & Kramer, 2008). The social connections developed through participation in team sports also make positive contributions to improved psychological well-being and self-esteem among youth (Daniels & Campbell, 2006; Dunton et al., 2007).

Across Nunavut, hip-hop culture and dance are very popular among youth. Children and youth in some communities form their own hip-hop dance clubs, regional workshops, and "battles" with support of an organization from Ottawa (BluePrintForLife, www.blueprintforlife.ca). During community consultations for this study, youth informants identified hip-hop as a fun, social physical activity, which they would like to see included in a youth intervention model.

While engaging youth in physical activity fosters awareness about the body's physical presence, mindfulness relaxation techniques were also identified in the literature as important tools to promote awareness of the connection between body, mind, and spirit, techniques to which community members responded very positively in the community dialogues. Mindfulness-based stress reduction and relaxation programs have been shown to enhance psychosocial well-

being and have become increasingly popular in school settings, young offender programs, and youth treatment centres to reduce stress and enhance overall well-being among youth (Biegel, Brown, Shapiro, & Schubert, 2009; Bogels, Hoogstad, van Dun, Scutter, & Restifo, 2008; Fang et al., 2010; Lawson, 2008). The ability to self-soothe and become calm in a stressful or agitating situation can be empowering and contribute to decreased stress, anxiety, and impulsivity, and can help with regulation of mood and/or emotion (Fang et al., 2010). The community dialogues suggested that the model should promote the practice of relaxation skills through teaching mindfulness-based stress reduction, yoga, and stretching.

Stress, coping, and the role of the home environment. The home environment plays an important role in the development of children and teens. It has been shown that healthy expression of emotions by parents and guardians can influence a youth's emotional regulation (Aldrich & Tenenbaum, 2006; Morris, Silk, Steinberg, Myers, & Robinson, 2007). Recent studies on family stability and stress levels among children have shown that significantly lower levels of cortisol (stress hormone) are found in children residing in homes with consistent, healthy emotional expression among the family members, and with mothers who exhibit low levels of depressive symptoms (Lupien, King, Mealney, & McEwan, 2002). In a study about the perspectives of Grade 9 students at one high school in Nunavut on the topic of sexual health and relationships, youth highlighted poverty, financial troubles at home, alcohol and drug use among their parents, and resulting interactions with the police as very stressful daily life events, which have an impact on their relationships and overall well-being (Healey, 2012). Stress reduction strategies, outlets for emotional expression, and skills for supporting positive reciprocal relationships are woven into the Eight *Ujarait*/Rocks Model. These strategies enhance the development of skills for managing internalized stress and can provide youth with alternative coping tools.

Mentorship: Connecting with and learning from someone. Mentoring among older youth and early adolescents, adults, and elders has been associated with better attendance at school and better attitudes towards school; lowered levels of substance abuse; positive social attitudes and relationships; and improved psychological well-being (Jekielek, Moore, Hair, & Scarupa, 2002; Qaujigiartiit Health Research Centre & Arviat Community Wellness Committee, 2015; Styles & Morrow, 1992). Programs such as Big Brothers Big Sisters of Canada, which support increased involvement in postsecondary education and promote awareness of unhealthy behaviours such as substance abuse, have included mentorship as a strong component of their models. Community members and elders in Nunavut provide mentorship by sharing their knowledge, skills, and experiences while, in turn, learning from the youth and offering opportunities for observation and questions. One elder who provided feedback on the model indicated, "I went to residential school. So I never got to be a youth. Now I get to be with youth, and I can [share in] the joys of the teen years that were taken from me." This perspective

underscores the reciprocal nature of the relationships that are formed through mentorship—the youth learn from the elders and the elders learn from the youth.

Coping skills and problem solving: The importance of self-expression. In the community dialogues, high rates of substance use, addictions, and suicides among youth were attributed to the need for youth to develop coping skills. Respondents attributed the lack of coping skills among youth to the traumas experienced by the parents during the (re)settlement events, tuberculosis evacuations, and residential school. Research into adolescent coping focuses on adaptive and maladaptive approaches to dealing with life, stress, family dysfunction, and social stressors (Recklitis & Noam, 1999). Andrews, Ainley, and Frydenburg (2004) discussed three styles of coping including (a) solving the problem (maintaining a positive outlook and taking steps to solve the problem), (b) reference to others (seeking support from others), and (c) non-productive coping (ignoring the problem, worrying, and wishing the problem away). Positive outlets for coping, self-expression, and contemplation among youth can include, but are not limited to, music, physical activity, social networking, engaging in cultural activities and traditions associated with cultural identity, group/club membership, talking to others, being creative, journaling, practicing relaxation skills, and generating solutions to problems (Tyson, 2002; von Georgi, Gobel, & Gebhardt, 2009). Coping skills, problem solving, and self-expression all work to support a young person's self-esteem and sense of self-efficacy, which is one of the goals for the model for youth mental health interventions in Nunavut.

Self-esteem. Self-esteem was identified in the literature and in the community dialogues as a core area of focus for youth programs. Having an understanding of and positive feelings toward one's own skills and abilities is an important part of self-esteem among youth (Eccles et al., 1989). Changes in self-esteem can be observed over time, for example with transitions from elementary to junior high school to high school settings. Mastering a skill, feeling connected to others socially, maintaining a consistent identity, and having access to a variety of coping methods all contribute to positive adolescent self-esteem (Daniels & Campbell, 2006; Eccles et al., 1989). Froh, Sefick, and Emmons (2008) found that teens who were engaged in helpful activities that gave back to the community reported enhanced gratitude, optimism, and life satisfaction and decreased negative affect (mood). For this reason, one of the core activities in the model was related to making a positive contribution to one's community to (a) provide an opportunity to demonstrate capabilities and strengths, (b) bring joy to others in the community, and (c) increase self-esteem among youth.

The Eight *Ujarait*/Rocks Model

This model for youth mental health and wellness interventions was designed to respond to the needs of Nunavut youth during a critical stage of adolescent development. It was grounded in research, best practice, and community perspective. As former Nunavut youth and current youth advocates, the authors designed the model based on all the available evidence as well as their own stories and experience. *Ujaraq* is the Inuktitut word for "rock" (*ujarait* is plural). The

Eight *Ujarait*/Rocks Model highlights eight core constructs, which symbolize the formation of a solid stone foundation comprising skills and knowledge upon which young people build their lives. The eight *ujarait* are visualized in the form of a ring, which is a common formation on the land in the Arctic, where the stones have been used to hold down the base of a tent (Figure 1).

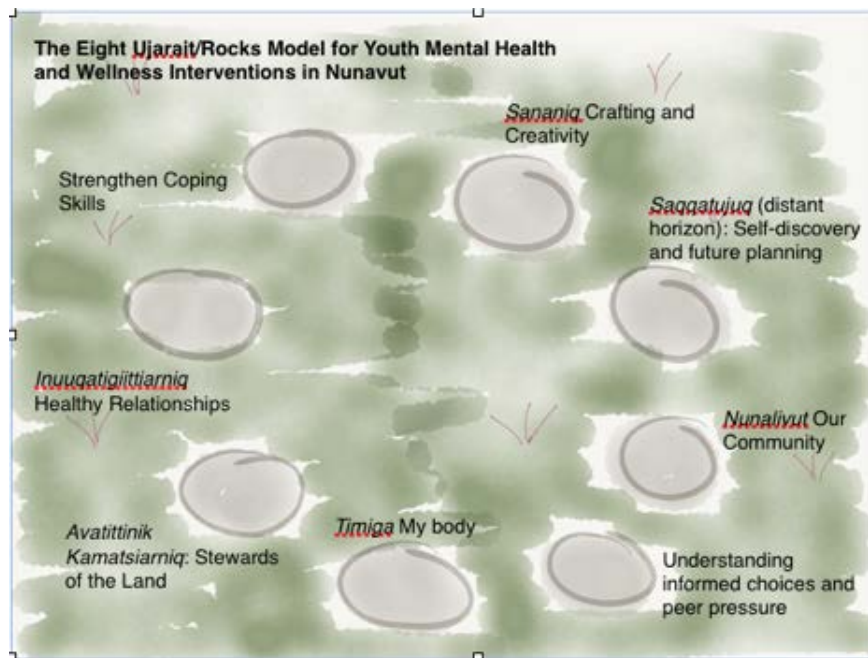


Figure 1. The Eight *Ujarait*/Rocks Model for youth mental health and wellness interventions in Nunavut.

The eight evidence-based modules or *ujarait* are the following:

- Module/*Ujaraq* 1: Strengthening Coping Skills
- Module/*Ujaraq* 2, *Inuuqatigiittiarniq* (being respectful of others): Building Healthy and Harmonious Relationships
- Module/*Ujaraq* 3, *Timiga* (my body): Nurturing Awareness of the Body, Movement, and Nutrition
- Module/*Ujaraq* 4, *Sananiq*: Crafting and Exploring Creativity
- Module/*Ujaraq* 5, *Nunaliyut* (our community): Fostering Personal and Community Wellness
- Module/*Ujaraq* 6, *Saqqatujuq* (distant horizon): Self-discovery and Future Planning
- Module/*Ujaraq* 7: Understanding Informed Choices and Peer Pressure
- Module/*Ujaraq* 8, *Avatittinik Kamatsiarniq* (stewards of the land): Connecting Knowledge and Skills on the Land

The modules/*ujarait* promote positive social interactions (Modules 1, 2, 5, 7, and 8); opportunities for self-reflection and self-expression (Modules 2, 4, 6, and 8); cultural skill-

building (Modules 3, 4, and 8); and exploring the relationship between healthy minds and bodies (Modules 3 and 7). They are delivered in a positive, respectful, strengths-based, solution-oriented space. The model also emulates the aforementioned concept of *pilimmaksarniq*, which is the development of skills through effort and practice—a critical concept in understanding Inuit ways of knowing. Each module incorporates hands-on activities in a fun and enriching learning environment. The Nunaliivut module directs youth toward collectively addressing a community by contributing time and energy to an activity, such as visiting elders; helping clean their community by picking up garbage; volunteering at the animal shelter, thrift shop, or soup kitchen; or baking and giving food to someone in need. The *Timiga* module focuses on the body, physical activity, and nutrition, including the practice of Inuit games and traditional activities, such as hunting, harvesting fish, hiking, berry picking, egg picking, cleaning and caring for the campsite, etc., which naturally involve body movement. The need for mentorship is addressed in the Eight *Ujarait*/Rocks Model by encouraging two older youth mentors or peer leaders to join the intervention leadership team, acting as role models and supporting the intervention's implementation.

Early Results of Model Implementation

Early findings indicate that the activities in the program fostered physical, mental, emotional, and spiritual wellness and supported a holistic perspective of wellness. The camp promoted knowledge sharing with community members and role models, thereby strengthening relationships between youth and members of the community. These relationships are important connections for youth as they move into adulthood. Campers described it as “an experience of a lifetime” and said that they learned how to deal with different emotions. Overall, the camp promoted team building with peers, a sense of unity among the group, and connection to the community at large. Campers reported that it was fun and educational and that they gained an increased interest in participating in community and land-based activities after the camp, they valued the land, and they valued the role of the land/water in Inuit culture. Campers reported feeling more happy, cheerful, and energetic and less sad after participation in the camp. Campers indicated that they understood their personal strengths and felt better prepared to plan for their future and set goals for themselves.

Parents reported seeing significant positive behaviour and attitude changes in their children. Parents expressed pride for the camp program itself, appreciated that it was developed by Nunavummiut for Nunavummiut, and felt that the values and knowledge shared in the camp were indicative of this. Parents wanted to see the camp continue and expressed that continuity of the camp was extremely important to them, and that it should be offered through schools as well as in the community. Parents indicated that their children were more helpful, happy, and aware of respecting others. They reported observing an increase in confidence in their children and that the children were better prepared to deal with difficult situations. Parents stated that the camp created an opportunity for youth to make friends, relax their minds, participate in more activities, and increase independence; they felt that the camp was a good experience for youth.

Discussion

There has been an increasing movement in prevention science to study the cultural adaptation of interventions (Backer, 2002; Castro, Barrera, & Martinez, 2004; Kumpfer, Alvarado, Smith, & Bellamy, 2002). At the same time, a dialogue is emerging about the tension between the implementation of an intervention as intended by the developer (fidelity), and the modification of the program based on the specific needs of a target group (adaptation; Castro et al., 2004). Within the literature on family-based interventions with First Nations, Inuit, and Métis people, the process tends to begin with the identification of a sound intervention designed for a specific population, which is then adapted to be inclusive of the sociocultural expectations of the target First Nations, Inuit, and/or Métis group. For this study, we reversed this process, instead focusing on the development, implementation, and evaluation of an intervention model designed by and for Nunavummiut. The intervention model was embedded in the social context, language, and values of the population for whom it was designed. The results demonstrate that evidence-based, community-driven models for youth mental health interventions in the North hold extraordinary promise.

Inuit families living in the Canadian Arctic experienced a number of relocation events in the 1950s and 1960s during the resettlement program, residential school period, and tuberculosis-related medical evacuations, which disrupted kinship groups and disconnected families (Healey, 2015). One of the important findings of this study is that application of the model through a camp program had an impact on the individuals involved beyond their immediate participation in the program. The implementation of this model has positively impacted family and community relationships and promoted enduring Inuit values such as connection to immediate and extended family, the community, and the land.

This article provides only one perspective on a highly complex issue that is in constant flux. The needs of Nunavut youth are altered as our communities continue to rapidly change. Future research should critically examine youth mental health intervention models and the philosophical and cultural assumptions implicit in their delivery. Long-term monitoring of the participants in this study, and ongoing evaluations of the Eight *Ujarait*/Rocks Model as it continues to be applied, are needed to contribute to the robust evidence base for this model over time.

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Sharing Our Wisdom: A Holistic Aboriginal Health Initiative

Abstract

Colonization has had a profound effect on Aboriginal people's health and the deterioration of traditional Aboriginal healthcare systems. Health problems among Aboriginal people are increasing at an alarming pace, while recovery from these problems tends to be poorer than among other Canadians. Aboriginal people residing in urban settings, while maintaining strong cultural orientations, also face challenges in finding mentors, role models, and cultural services, all of which are key determinants of health. Using a participatory action framework, this study focused on understanding and describing Aboriginal traditional healing methods as viable approaches to improve health outcomes in an urban Aboriginal community. This research investigated the following questions: (a) Do traditional Aboriginal health practices provide a more meaningful way of addressing health strategies for Aboriginal people? (b) How does participation in health circles, based on Aboriginal traditional knowledge, impact the health of urban Aboriginal people? Community members who participated in this project emphasized the value of a cultural approach to health and wellness. The project provided a land-based cultural introduction to being of *náca?mat tə šx^wq^weləwən ct* (one heart, one mind) and learning ways of respectful listening *x^wna:mstəm* (witness) *tə slaxən* (medicines) (listen to the medicine), through a series of seven health circles. The circles, developed by Aboriginal knowledge keepers, fostered a healthy sense of identity for participants and demonstrated the ways of cultural belonging and community. Participants acknowledged that attending the health circles improved not only their physical health, but also their mental, emotional, and spiritual health.

Keywords

Traditional Aboriginal health practices, holistic health, traditional Aboriginal knowledge, health inequity, health outcomes, community-based healing, participatory action research, urban Aboriginal health

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Introduction

Aboriginal people¹ have been profoundly affected by the adverse consequences of colonization and have struggled to survive in a Western world while enduring continual assimilation attempts, including residential schools, the reserve system, and cultural oppression (Chisholm, 1994; Ellis, 1994; Hart, 2002). Colonization has had a profound effect on Aboriginal people's health and the deterioration of traditional Aboriginal healthcare systems. Statistics indicate that health disparities exist between Aboriginal people and other Canadians (Adelson, 2005), and health strategies to date appear to be minimally effective in improving their health. The health outcomes and health disparities for Aboriginal people are discouraging, with direct impacts from poverty, gaps in education status, urbanization, relocation from traditional territories, and cultural oppression (King, 2009).

Health problems among Aboriginal people are increasing at an alarming pace, while recovery from these problems tends to be poorer than among other Canadians. Many indicators, including life expectancy, infant mortality, birth weights, and crude mortality, illustrate that

¹ For the purpose of this paper, "Aboriginal people" includes First Nations (Status and Non-Status), Métis, and Inuit people.

Aboriginal people are burdened with a variety of health inequities in Canada (Health Council of Canada, 2005). Recent attention has also been paid to the rapidly rising rates of chronic disease, including diabetes, heart disease, and hypertension, within the Aboriginal population (British Columbia Provincial Health Officer, 2009; Health Council of Canada, 2012). Numerous documents have discussed the disparities and inequities between the Aboriginal population and non-Aboriginal population in Canada, which have manifested from ongoing attempts at assimilation, cultural oppression, and systemic racism (Frohlich, Ross, & Richmond, 2006). Frohlich et al. (2006) stated:

These health disparities have manifested from a long history of oppression, systemic racism, and discrimination, and are inextricably linked to unequal access to resources such as education, training and employment, social and healthcare facilities and limited access to and control over lands and resources. (p. 136)

The majority of Canadian medical healthcare systems reflect colonial perspectives and practices and create culturally unsafe and unwelcoming environments for Aboriginal people. Likewise, most healthcare services within Canada are implemented without considering or respecting Indigenous knowledge of healing and wellness. The World Health Organization's (2000) definition of traditional medicine is the "sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness" (p. 1). Traditional healthcare practices are often disregarded within the Canadian medical system, yet research repeatedly supports their value (Martin Hill, 2009; McCabe, 2007; McCormick, 1995). Additionally, studies have demonstrated that Aboriginal communities and organizations have a great desire to integrate traditional healthcare practices into the larger healthcare system (Earle, 2011; First Nations Health Society, 2010).

Health disparities caused by colonization and its impacts have also affected Indigenous health knowledge as well as knowledge related to identity. An important aspect of colonization that warrants discussion is the impact that *knowledge nullification* has had on Indigenous knowledge. One of the authors of this paper, Dr. Brown coined the term *knowledge nullification* to represent the policies and procedures that have devalued Aboriginal knowledge. Wilson (2003) emphasized that colonizers thought that Aboriginal peoples' traditions and knowledge were worthless and inferior to those of the dominant culture. Belief in the inferiority of Aboriginal knowledge was embedded in governmental policies that nullified the validity and existence of Aboriginal knowledge, and to this day, Canadian processes of health promotion are often implemented without considering or respecting Indigenous knowledge of healing and wellness. According to Letendre (2002),

the blatant disregard, and perhaps true ignorance, for the consequences that this major shift in health ideologies would impose on the Aboriginal population of Canada resulted in an almost complete loss of Aboriginal traditional medicine ... This loss of traditional

medicine has resulted in devastating consequences for the Aboriginal people as evidenced by the inappropriate attempts and subsequent failures of modern medicine to improve the health status of the Aboriginal community. (p. 80)

This imposition of Canadian culture continues to oppress Aboriginal people; it is vital to acknowledge this consequence of colonization and the positive influence of creating space for the promotion of Indigenous knowledge in decolonization processes that contribute to health promotion and wellness for Aboriginal people.

There are also critical distinctions between Aboriginal and traditional Western science and how health, wellness, and illness are defined. Where the Aboriginal health model is holistic and encompasses four dimensions of health (physical, mental, emotional, and spiritual well-being), the Western biomedical concept of health often concentrates on disease and infirmity. Adelson (2005) noted that in the biomedical model, resources and programs often exist only when one experiences illness and that, patients are passive and compliant recipients of treatment. From an Aboriginal perspective, a more comprehensive holistic understanding is necessary to acknowledge the four dimensions of one's being, extending beyond the individual to include family and community. A focus on lived wellness is more proactive, less reactive, and more conducive to healing than present practices that emphasize a program approach based on the biomedical model of health. Innovative solutions to health problems are vital. One of the most efficient and proven ways to accomplish this is the delivery of culturally appropriate healthcare (Martin Hill, 2009; McCabe, 2007; McCormick, 1995; Weaver, 2002). An Aboriginal, holistic approach to healthcare that includes the four dimensions of health, as well as proactive engagement in wellness, can substantially improve quality of life, reduce the risk of chronic disease, improve health outcomes, and reduce overall healthcare costs.

Aboriginal people residing in urban settings, while maintaining strong cultural orientations (Peters, 2011), face challenges in finding mentors, role models (Environics Institute, 2010), and cultural services, all of which are key determinants of health (World Health Organization, 2016). The need to access Aboriginal health knowledge and practice has been a priority for the Vancouver urban Aboriginal community for many decades. In 1999, the Vancouver/Richmond Health Board completed an Aboriginal health and service review called *Healing Ways*. Hundreds of community members participated in the review. One of the findings indicated "support for a healing center" (p. 7), stressing the value of traditional Aboriginal healing strategies. In 2012, the Institute for Aboriginal Health in the College of Health Disciplines at the University of British Columbia completed a consultation process with the Vancouver urban Aboriginal community in a project titled "An Aboriginal Community Snapshot of Health and Research Needs" (ACSHRN; Richardson & Brown, 2012). With respect to a vision of good health, community members reported a need for a holistic balance of healthcare services based on the medicine wheel and for increased access to relevant programs and services (Richardson & Brown, 2012). Recently, St. Paul's Hospital in Vancouver conducted a community survey, with one of the resulting recommendations being the creation of a Sacred Space within the hospital, which was created with urban Aboriginal community guidance. These

are just a few local activities indicating that access to Aboriginal health knowledge, as a meaningful way to increase Aboriginal people's health, is a priority for Vancouver's urban Aboriginal community. Colonization, knowledge nullification, health disparities, and lack of access to Aboriginal health knowledge and practices have all also been prioritized. This research further responds to these priorities.

Research Purpose

Using a participatory action framework, in which researchers and community participants work toward change in policy and practice (Radermacher & Sonn, 2007), this grounded theory study focused on understanding and describing Aboriginal traditional healing methods as viable methods of improving health outcomes in an urban Aboriginal community. This research investigated the following questions: (a) Do Aboriginal traditional health practices provide a more meaningful way of addressing health strategies for Aboriginal people? (b) How does participation in health circles, based on Aboriginal traditional knowledge, impact the health of urban Aboriginal people? Through examining the meaning of Aboriginal knowledge and traditional healthcare practices within the urban Aboriginal community of Vancouver, Canada, this study aimed to illuminate the importance of increased access to traditional healthcare in order to inform policy and program delivery that can prove beneficial to Aboriginal people.

Relationship

This project began through consultation with and guidance from the urban Vancouver Aboriginal community. We formed an Aboriginal Health Working Group (AHWG), which consisted of approximately 15 Aboriginal Elders and/or community members who are experts in Aboriginal healthcare knowledge and practices. The AHWG is a diverse group representing many different nations from across Canada (e.g., Squamish, Lakota, Anishnaabe, Cree, St'át'imc), and their experiences of receiving healthcare also reflect the issues experienced by the urban Aboriginal population. We also ensured that we followed land-based protocols by inviting Elders from the local Coast Salish Peoples of Musqueam and Squamish (Gomes, Young Leon, & Brown, 2013). The AHWG provided invaluable guidance and knowledge throughout the entire project in areas such as curriculum development for the healthcare circles, healthcare circle facilitation, data analysis, and knowledge dissemination.

By developing the AHWG and consulting with community members, we affirmed the teachings of the four Rs—respect, reciprocity, responsibility, and relevance (Kirkness & Barnhardt, 1991)—and deem this a community-based Aboriginal methodology. *Respect* emphasizes the importance of including Aboriginal knowledge, beliefs, values, and traditions as guiding principles in the project. *Reciprocity* is a process of sharing, reporting, and giving back to the community and was embedded in the project (e.g., creating a holistic workshop curriculum that can be shared with community organizations). Both *responsibility* and *relevance* were demonstrated through using a participatory action approach, which allowed for participants to be empowered by playing an active role in the process and which ensured that the research was

valued and deemed necessary by the community. The value of relevance was largely demonstrated through the formation of the AHWG, consultation with the urban Aboriginal community concerning health and research needs (ACSHRN project), and knowledge translation strategies to validate the findings (a conference and feast with approximately 100 community members).

When bringing together the AHWG we were also informed by the principles of Indigenous leadership in health and of following *right relationship* (Gomes et al., 2013; Kirmayer & Valaskakis, 2009; Marsden, 2006; Smylie et al., 2009) Right relationship, a decolonizing process for settler and Indigenous relations, is based on respectful, reciprocal relationships, that protect cultural knowledge, and demonstrate our responsibility to follow local Indigenous protocols in our health leadership practices. This is the foundation for creating access to culturally appropriate health systems. The AHWG, community organizations, and ACSHRN participants have deemed this research as valuable and significant to the urban Aboriginal community. Also, statistics on health disparity and academic literature mentioned above would both suggest this as an important project.

Lastly, this research project was developed in partnership between an academic institution and a health authority and had protocols for supporting the resurgence of Indigenous leadership in health and for addressing cultural appropriation aspects (Gomes, Young & Brown, 2013). The key partnership members are also involved personally with the urban Aboriginal community, and had cultivated right relationships with all of the AHWG members. We also hired a cultural consultant to guide us through the cultural nuances and protocols involved in implementing the program and establishing relationships with all those involved. We worked together to formulate the grant application, which resulted in funding by the Vancouver Foundation. These important steps honoured the value of relationships and Aboriginal knowledge and were an excellent method to create, implement, and evaluate this project.

Methods

Program Design

Our goal was to create and provide a series of holistic health circles to Aboriginal community members in order to engage them in learning about Aboriginal healthcare practices, facilitate a healthier life context, work towards the prevention of risk factors for health issues, and validate and create a better understanding of the utility of traditional healing practices. After approximately 18 months of consultation and guidance from the AHWG, we developed seven holistic health circles grounded in traditional teachings and practices (see description below and Appendix). Once these health circles were developed, we approached Aboriginal Elders and experts who would present each of the topics, created a schedule for the program, and began recruiting participants. We had the opportunity to provide the seven-health-circle program twice, and offered the two programs 6 months apart.

Health circles. The program (see also Appendix) consisted of seven health circles that were grounded in Musqueam ideology. Even though we were a diverse urban Aboriginal group of knowledge keepers, the majority of the circles were held on Musqueam territory. Therefore, we turned to the Musqueam Elder involved in the AHWG to ground the whole context of the research in the Musqueam worldview of *ná'ca?mat tə šx^wq^weləwən ct* (one heart, one mind) and *x^wna:mstəm* (witness) *tə slaxen* (medicines) (listen to the medicine). The principles of coming together as one heart, one mind, by listening to the medicine and ancestors through the cultural teachings, to each other, and to *all our relations* would begin a return to being of good mind, good heart, good spirit, and good body. These principles provided the container to hold all the other topics introduced through the program and determined the sequential order:

1. Protocols and Place (respect)
2. Identity and Health (relationships, building identity)
3. Traditional Foods (food as medicine, relationships)
4. Emotional Competence (emotional health, responsibility)
5. Medicine Making (traditional medicines, relevance)
6. Drumming Circle (singing, drumming, relevance)
7. Spirit and Ceremony (spiritual health and wellness, reciprocity)

We chose the flow of the teachings based on land and protocols as the foundation, then cultural identity as key to healing (First Nations Health Society, 2010). The need for nurturing the body (food and medicines), heart (emotional competence), spirit (ceremony), and mind (knowledge of how to do the practices) were all essential parts in providing a holistic knowledge experience (Table 1).

Table 1
Holistic Health Circle Approach

Aspect	Health circle goals
Mental component	<ul style="list-style-type: none"> • Increasing health knowledge • Knowledge dissemination in key disease areas, such as cancer, arthritis, diabetes, cardiovascular disease • Validation of Aboriginal knowledge
Emotional component	<ul style="list-style-type: none"> • Creating emotional competency in our communities • Learning how to identify, manage, and express emotions in a healthy manner • Connecting emotions to health issues • Developing emotional skills essential to health • Creating the emotional foundation to physical, mental, and spiritual health
Physical component	<ul style="list-style-type: none"> • Nutrition/diet knowledge of Indigenous foods, herbs, and medicines (learning about healthy eating, diet, nutrition, and food preparation) • Garden project (sacred uses of tobacco and other medicines) • Importance of physical activity and exercise programs

Aspect	Health circle goals
Spiritual component	<ul style="list-style-type: none"> • Creating spiritual/cultural wellness • Role of spirit in health • Importance of traditional teachings and ceremony in health • Knowledge transference with Elders

A different Aboriginal Elder or traditional healer facilitated each of these life practices. Each Elder or traditional healer taught in their own style and shared teachings based on their protocols and teachings. We also attempted to have gender balance, so most of the health circles were co-facilitated. Some of the health circles were centred on talking circles, while others were more experiential. For example, during the medicine-making health circle, participants gathered on the unceded traditional Musqueam territory and were taken on a traditional medicine walk, where they were taught about indigenous plants that grow in this territory. They also participated in making medicinal tea blends and learned about how different medicines help different health issues and concerns (e.g., diabetes).

Procedure

Community members were recruited through various organizations, email contacts, and newsletters and were asked to contact the lead researcher. Criteria to participate included those who self-identified as an Aboriginal person; had an interest in attending the holistic health circles; were over the age of 19; were able to communicate in English; and committed to participating in all stages of research, including the health circles and follow-up talking circles. Once community members made contact, they were invited to a pre-workshop interview, in which they were informed of the details and schedule of the project and were asked to sign the consent form.

The health circles were presented in a workshop style, lasting 4 hours, on a weekly basis for 7 weeks. During each session, we provided a healthy meal and time to socialize before and after the health circle. Locations of the health circles changed depending on the topic (they could include a garden or health centre, for example). Participants were also provided with transportation costs to and from the circles, as well as a gift card to honour their time. Across the two cohorts that attended the health circles, there were 35 participants (Table 2).

Table 2
Community Member Participants in Two Health Circle Programs by Age, Identity, and Gender

Age	n	Identity				Gender	
		First Nations (status)	First Nations (non-status)	Métis	Other	Female	Male
Young people (18-29)	11	5	3	5	0	8	3

Age	n	Identity				Gender	
		First Nations (status)	First Nations (non-status)	Métis	Other	Female	Male
Adults (30-59)	19	13	4	1	1	10	9
Seniors (60 and older)	5	4	0	0	1	5	0
Total	35	20	7	6	2	23	12

Note: This data describes the participants that completed the circles (n = 35). Participants were able to select multiple identities, and two young people identified as both First Nations and Métis.

Research methods included weekly feedback forms to assess new knowledge, skills, and areas for improvement; a talking circle to discuss short-term outcomes (1 week after the programs, with 32/35 participants completing this talking circle. We also hosted a second talking circle to discuss intermediate outcomes (6 months after the programs, with 25/35 participants attending this). At each of the talking circles, participants also completed written surveys to measure changes in self-reported health and healthcare practices. Data from the talking circles were transcribed and thematically analyzed. The results were presented to the AHWG and in a community presentation for validation.

Results

Participants spoke about the short-term and longer-term impacts that the health circles had on their approaches to healthcare strategies and practices. While we gathered an immense amount of data from participants, other components of the findings are outside the scope of this paper. During analysis of the qualitative data for both short-term and intermediate outcomes, the themes that emerged across the different age groups (youth, adults, and seniors) were similar; the findings presented below represent voices across the entire range of participants.

Short-Term Outcomes

At the 1-week follow-up after each program, 11 major themes arose from the two talking circles (Table 3).

Table 3
Changes in Personal Healthcare Strategies and Practices 1 Week After the Health Circle Programs

Theme (Number of statements)	Example of statements
Traditional foods and medicines (n = 30)	Increased awareness of eating habits and importance of healthy foods; Increased awareness about having positive intention when preparing food; Drinking more water; Changed eating habits to include more nutritious/whole foods; Cooking and eating more traditional foods (using cookbook); Eating for your spirit; Talking to others about the importance of healthy foods; Learned more about traditional plants—will continue to learn; Paying more attention to teas; Continue to learn about and make traditional medicines (teas, oils, etc.)
Emotional and mental health and wellness (n = 27)	Learning how to communicate with others—listening but not feeding into negativity; Releasing or learning to control anger; Paying more attention to emotional wellness (branching out from focusing purely on physical health); Learning how to identify and address emotional health concerns, rather than covering them up; Journaling emotions and dreams
Spiritual health and wellness (n = 19)	Awareness about the spiritual connection to water and health, and practicing ceremony (e.g., shower cleansing, praying before drinking water); Joined (or would like to join) a drumming group to address spiritual health; Exploring spirituality, connecting with ceremonial leaders, and experiencing increased spiritual health; Praying more and noticing the positive benefits; Awareness of spiritual health for the first time; Generally applying spiritual practices in life
Community (n = 19)	The importance of community healing; Being connected to First Nations healers and Elders—knowing that you can ask them questions and that they will guide you; Forming community through the weekly groups, sharing a journey of gaining knowledge and strengthening identities; Understanding that connection and belonging are really important in an urban context; Becoming more involved in the community
Empowerment and identity (n = 14)	Increased empowerment over health and choices in healthcare; Evaluating and taking control over own social environment, removing negativity from life; Empowerment through strengthened identity; Paying more attention to self-care
Physical health and wellness (n = 8)	Feeling more in touch with their bodies; increased physical activity
Colonization (n = 5)	Awareness of the impacts of colonization on language, health, and culture; Healing from the impacts of attending residential school; Lacking access to culture when living in an urban environment
New knowledge (n = 5)	Workshops were a reminder of past knowledge (e.g., teachings from childhood)—bringing it forward; Understanding the importance of traditional healing; Importance of experiential learning

Theme <i>(Number of statements)</i>	Example of statements
Substance use (<i>n</i> = 4)	Quit drinking alcohol completely; Drinking less alcohol, understanding its impacts on health, making choices to spend money on other things; Stopped smoking marijuana
General health improvement (<i>n</i> = 3)	More balanced—emotionally, spiritually, physically, and mentally; A lot of health issues cleared up over the process of taking the workshops
Language (<i>n</i> = 1)	Learning new words from the Elders and finding these words in own language
Total (<i>N</i> = 135)	The 32 participants at the 1-week follow-up talking circles reported a total of 135 ways in which their healthcare strategies and practices have changed.

Most commonly, participants spoke about traditional foods and medicines (*n* = 30). They spoke about having an increased understanding of their eating habits and the need to eat healthy foods, as well as about sharing this knowledge with others. Participants also spoke about drinking more water, using traditional teas, and continuing to learn about traditional medicines. One participant noted that they would be using their new knowledge to learn about the medicines in their traditional territory:

I wrote down all the ingredients ... even though I'm here I still want to learn about my medicines from home. So from participating in the medicine-making workshop, I wanted to learn more about my own people's medicines.

A second theme concerned emotional and mental health and wellness (*n* = 27). Participants spoke about new communication skills, the ability to release and control anger, and learning how to identify and address emotional health needs. They also reported that they were paying more attention to their emotional wellness, rather than focusing purely on physical health. Related to this, one participant spoke about the importance of evaluating the impact of social networks on emotional and mental wellness:

I'm evaluating who I'm spending my time with and what they bring and what I contribute to them. I've decided to move away from circles that bring negativity like drinking. It brings out a bad side ...

Spiritual health and wellness also arose as a prominent theme (*n* = 19). Participants spoke about the ceremony and spiritual teachings that they gained from the health circles, and the impacts that they have had on their health. In particular, they cited the connection between water, ceremony, and health; new interest in drumming groups for spiritual wellness; and the importance of connecting with spiritual leaders in the community. Related to this, community was also a prominent theme (*n* = 19), where discussions included the importance of community healing, connecting with Aboriginal healers and Elders, and having a new sense of community

through the weekly health circles. Participants also spoke about increased understanding that connection and belonging are really important in an urban context. Additional themes were empowerment and identity, colonization, physical health and wellness, new knowledge, substance use, general health improvements, and language (Table 3).

Intermediate Outcomes

Data on intermediate outcomes from the 6-month follow-up talking circles revealed 10 major themes (Table 4).

Table 4
Changes in Personal Healthcare Strategies and Practices 6 Months after the Health Circle Programs

Theme <i>(Number of statements)</i>	Example of Statements
Traditional foods and medicines (<i>n</i> = 18)	Using traditional teas for health; More conscious of eating food as medicine (e.g., understanding links between food and diabetes/cancer); Increased knowledge about the value of traditional medicine; More knowledge of plants as medicines; Finding places to access traditional medicines in the city
Spiritual health and wellness (<i>n</i> = 16)	Making time for ceremony, attending more ceremonies; Smudging more (e.g., for reducing stress); Participating in cultural activities (e.g., drum-making, drumming, dancing)
Emotional and mental health and wellness (<i>n</i> = 11)	Being more gentle with myself; Being more present, grounded—following the lead of the Elders and traditional healers; Mental health outcomes have improved (reduced depression, less reliance on antidepressants); Doing art more as therapy—traditional art forms; Removing self from negativity and gossip
Empowerment and identity (<i>n</i> = 6)	More confidence in self, wellness, and Aboriginal identity; Revitalizing teachings and traditions from community—feeling empowered to do this, overcoming the history of community relocation and ceremonial bans; Not feeling alone in struggles with identity
Community (<i>n</i> = 4)	Noticed that the people around me take care of themselves better too; Understanding that people are medicine
Colonization (<i>n</i> = 4)	Understanding the impacts of colonization on health and ways of fighting back through revitalizing culture; Understanding the general impacts of colonial mentalities—workshops were inspiring but it is hard to continually find opportunity to uphold this
Access to traditional healthcare (<i>n</i> = 4)	Frustrations trying to get traditional healthcare—there is not enough out there/not aligned with the system; Circles were amazing but need more opportunities to practice culture as healing (e.g., more venues, more programs); Made more of an effort to seek out a traditional healer in the community to learn more about medicines and plants
Physical health and wellness (<i>n</i> = 4)	More physical activity—walking early morning, strength training

Theme <i>(Number of statements)</i>	Example of Statements
Elders and traditional healers <i>(n = 2)</i>	Have reached out to find Elders to learn from
Protocols <i>(n = 1)</i>	Increased knowledge of protocols for cultural activities (e.g., hunting in others' territory)
Total <i>(N = 70)</i>	The 23 participants at the 6-month follow-up talking circles reported a total of 70 ways in which their healthcare practices have changed.

As with the short-term outcomes, many participants spoke about changes in their healthcare practices in relation to traditional foods and medicines ($n = 18$), such as increased use of traditional teas as medicine, increased healthy eating, and better understanding of the link between food and wellness (and disease). Participants also spoke about making increased efforts to access traditional medicines in the city:

I've made more of an effort to seek out a traditional healer in the community to learn more about medicines and plants.

Spiritual health and wellness also arose as a prominent theme for the intermediate findings ($n = 16$). Participants spoke about making time for ceremonies and participating in cultural activities. The third theme for the intermediate findings was emotional and mental health and wellness ($n = 11$). Participants noted that they were being gentler with themselves, being present and grounded, and removing themselves from negativity and gossip. Others noted that they had experienced improved mental health outcomes, such as reduced depression and less reliance on antidepressants.

It is also important to note that empowerment and identity arose through the intermediate findings ($n = 6$), as participants spoke about having increased confidence, empowerment, and a stronger sense of identity as Aboriginal people. As well, participants spoke about learning that they are not alone in their struggles with identity:

Participating in the circles has given me confidence in myself, my wellness, and my Aboriginal identity ... I learned that many people have struggled with Aboriginal identity ...

Related to this, another participant captured the connection between the Elders' teachings, identity, and future generations and the connection to health:

We are a new generation, thankful for our grandmothers for holding on to our identity so they can pass it on today. Listening to the Elders at these workshops is very powerful ... We are learning for the next generation. The health of our people is getting stronger; it's going to be a long journey until we're strong. With the help of workshops like this, it makes our people stronger. Anything that can bring wisdom and identity together, it can

make our people stronger. I'll be able to pass the words of the Elders on to my grandchildren and that's powerful.

Additional themes were community, colonization, access to traditional healthcare, physical health and wellness, working with Elders and traditional healers, and understanding protocols.

Limitations

There are two limitations that we hope to overcome in future research. First, the program we offered was only 7 weeks long. Although this was a good introduction to Aboriginal healthcare practices for most participants, they also informed us that they would have preferred a longer program and indicated that they would benefit from more programming like this. A challenge for many programs that begin to see success is the lack of funding for the program to continue. Although community members were aware that the program was time limited, once they began, they wanted to continue. We hope that this research will support sustainable funding for Aboriginal healthcare programs that are easily accessible to the Aboriginal community. Second, this research relies on self-reported data, which may be impacted by social desirability (Kaminska & Foulsham, 2013). Although self-reported data are not without challenges, for the purposes of this study, they allowed us to capture the voices of the community.

Discussion

The findings indicate that participants benefited from attending the health circles and have begun to incorporate what they learned in the health circles into their daily lives. The findings are encouraging and support the use of traditional healthcare practices within urban settings as ways of increasing positive health outcomes for Aboriginal people. Holistic healthcare programs developed with the principles of Aboriginal leadership and decolonizing right relationships with Aboriginal people can begin to redress the health disparities prolonged by colonial structures. By being centered within Aboriginal worldviews and practices, these programs are culturally meaningful and provide a sense of community and belonging that will change some of the systemic barriers and health inequities experienced by the urban Aboriginal community.

The connection of land and culture to health and place is important in everyday life for Aboriginal people (Panelli & Tipa, 2007; Richmond & Ross, 2009; Wilson, 2003). This connection can be particularly challenging for Aboriginal people in urban settings. This study, by holding some of the health circles on the urban lands of the Musqueam Nation and providing access to the Indigenous farmland at the University of British Columbia, also situated the learning experience within the Aboriginal concepts of *ná'ca?mat tə šx^wq^weləwən ct* (one heart, one mind) and learning ways of respectful listening *x^wna:mstəm* (witness) *tə slaxen* (medicines) (listen to the medicine). These land- and culture-based practices are the foundation for the maintenance of strong cultural identities and the empowerment of personal healthcare.

Holistic Health

This project allowed participants to learn about self, spirit, and culture and the role they have in strengthening identity, emotional competency, and self-esteem, all of which are important for holistic health. The health circles were developed from a holistic perspective, and the importance of mental, emotional, spiritual, and physical health were emphasized by the Elders and traditional knowledge keepers. The value of holistic health can be seen in the themes that emerged in the research results, as each of these components was acknowledged when participants spoke about the impact of the health circles on their healthcare strategies. In both the short-term and intermediate findings, participants commonly indicated that the health circles impacted their cultural knowledge, emotional competency, spiritual health, and physical health. Participants stressed the importance of holistic healthcare in many ways:

I believe that for me, I have started to pay attention to my cultural aspect and am paying attention to wellness and health ... I never thought about health and wellness before, but now I do. Now I pay attention. Now I think about it.

It is important to have holistic traditional healthcare practices accessible for the people ... recognize that it should be available within healthcare ... Recognize that it's there.

The results demonstrate the benefits of engaging in and learning about health and wellness. They also illustrate that health and wellness are inclusive of a healthy mind, emotional context for life, spiritual energy, and zest for life in a healthy physical body. Unfortunately, most healthcare services do not include these aspects of wellness, and Aboriginal knowledge is often neglected within the dominant healthcare system (Adelson, 2005). This project reaffirms the value of utilizing an Aboriginal approach to health and wellness and the value of traditional knowledge, medicines, and systems of healthcare and is supported by decades of similar research. In 1995, McCormick reported that when he interviewed 50 Aboriginal people about their healing, “the First Nations world view as represented by the Medicine Wheel has balance as one of the basic tenets of healthy living” (p. 259). According to Medicine Wheel teachings, to obtain balance, an integration of all four quadrants of (mental, spiritual, emotional, and physical) is required. This balance can occur only when the individual is integrated and connected with family, friends, community, Elders, spirituality, traditional ceremonies, Mother Earth, and the Creator (Mulcahy, 1999). Programs need to honour these and other Indigenous teachings and ways of managing healthcare.

Community, Belonging, Identity, and Knowledge

The community members in this study also emphasized the value of Elders and traditional teachings/approaches to healthcare, and the significant role that feeling like part of a healthy cultural community played in their health and wellness. They also spoke about the importance of healing as a group: “The communal aspect of healing goes much further than one

on one.” Related to this, participants described the value of a strong cultural identity and the subsequent strengthening of health:

All this contributes to my growth as to my identity, and when it comes to my health, it's about who I am. So I thank the workshops and talking to Elders, I am so blessed to have these Elders to speak to ... Elders they open other directions for you and I think that makes a better growth for you spiritually. I think the workshops have been very important. For me, they've opened other directions of thinking. When you put them all together they all work towards better spiritual health, better identity.

Much of what the participants shared is interconnected and does not point to just one thing that was effective; it was the combination of being able to have access to Elders and traditional teachers, being able to learn and participate in a holistic healthcare system, and being able to gain Aboriginal knowledge that contributed to positive health outcomes. For example, one participant mentioned that, in reference to traditional healthcare knowledge, we should “always be looking for ways to let knowledge-keepers pass on their knowledge ... and for people who are interested in learning to have opportunities to do so. Validating that this is important for our people.” These findings align with past studies, which have demonstrated the importance of community and identity for Aboriginal people living within an urban environment and their access to safe and responsive healthcare (Van Herk, Smith, & Tedford Gold, 2012). It is encouraging to know that the community members who participated in this research were able to articulate these ideas and that their experiences will be able to shape future policy and programming in Aboriginal health.

Conclusions

Community members who participated in this project emphasized the value of a cultural, land-based approach to health and wellness. They acknowledged that attending the seven health circles improved not only their physical health, but also their mental, emotional, and spiritual health. The cultural introduction to being of *náca?mat tə šx^wq^weləwən ct* (one heart, one mind) and learning ways of respectful listening *x^wna:mstəm* (witness) *tə slaxen* (medicines) (listen to the medicine) fostered a healthy sense of identity for participants and demonstrated the value of cultural belonging and community.

Health inequities between Aboriginal and non-Aboriginal people are discouraging; yet this project emphasizes the value of Aboriginal leadership in providing traditional healthcare knowledge and practices to strengthen Aboriginal people's health and wellness. Our study also acknowledges the importance of having structures within Canadian healthcare settings which support and guide healthcare staff in working with Aboriginal leaders in providing access to cultural services while also protecting cultural knowledge. The health authority partner recently developed (in partnership with local Aboriginal communities) a cultural competency policy outlining the principles of Aboriginal leadership for their organization, VCH Aboriginal Cultural Competency Policy CA_5200, July 3rd, 2015, Internal Document. This policy provides the pathways on how to incorporate Aboriginal health practices, led by Aboriginal people, for

Aboriginal people. When such culturally meaningful programs are implemented for Aboriginal people, their health outcomes will improve.

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Appendix Holistic Health Circles (7 Weeks of Programming)

Outputs	Outcomes (Intended Impacts)		
	Short-Term	Intermediate	Long-Term
<i>What we do</i> (e.g., workshop details, etc.)	<i>Learning</i> (e.g., awareness, knowledge, attitudes, skills, opinions, aspirations, motivations)	<i>Action</i> (e.g., behaviours, practice decisions, policies, social, action,)	<i>Conditions</i> (e.g., social, economic, civic, environmental, etc.)
Health Circle 1: Respect— Protocols & Place - Cleansing ceremonies, brushing activity - Place names - Relationship to water - Cedar and	- Participants will gain a better understanding of protocol, specifically to land and place - Participants will gain knowledge of Musqueam historical and contemporary relationships to the territory - Participants will have increased awareness of the territory (i.e., place names, traditional territories, land-based practices)	- Participants will be able to express gratitude to the land - Participants will have increased participation in cultural health expressions - Participants will actively share this new knowledge with others in their communities	- Barriers to access to healthcare will be reduced - Participants will develop relationships with all beings and the land - Participants will have an enhanced sense of belonging and connection - Participants will

Outputs	Outcomes (Intended Impacts)		
Health Circle (Activities)	Short-Term	Intermediate	Long-Term
wellness	<ul style="list-style-type: none"> - Participants will understand how protocols, relationship, and ceremonies lower barriers and facilitate overall wellness strategies/skills 		<ul style="list-style-type: none"> have an increased sense of self-esteem and self-worth
<p>Health Circle 2: Relationships— Identity & Health</p> <ul style="list-style-type: none"> - History of health review - The importance of names - Cultural concepts of wellness - Relationship, identity, and cultural expressions 	<ul style="list-style-type: none"> - Participants will understand personal and cultural identity, and how this is linked to relationships with people, history, and overall health knowledge - Participants will have an understanding of how our identities are impacted by the systems we live in (i.e., colonization and disrespect, or connectedness and ceremony) and how these impact our health - Participants will gain awareness of holistic health and how cultural practices and community connectedness can contribute to our health 	<ul style="list-style-type: none"> - Participants will make informed decisions about their healthcare - Participants will actively share this new knowledge with others in their communities 	<ul style="list-style-type: none"> - Participants will have an increased sense of connectedness between our history, our health, and what we do within our culture and society in both present and future - Participants will have an increased sense of identity - Participants will have an increased sense of self-esteem and self-worth
<p>Health Circle 3: Relevance — Physical Body (internal) Traditional Foods</p> <ul style="list-style-type: none"> - Connection to land and holistic health - Specific health concerns and the nutritional value of foods - Feast 	<ul style="list-style-type: none"> - Participants will gain an understanding of food as medicine - Participants will gain an understanding of how what we eat is linked to the body’s performance, activity, and energy generation for dealing with their mental and emotional wellness (e.g., stress management) - Participants will have enhanced knowledge of specific foods and their connection to health, as well as the general benefits of being active and eating well (health promotion) - Participants will have increased knowledge of the importance of traditional foods in relationship with industrially processed foods 	<ul style="list-style-type: none"> - Participants will actively engage in ongoing discussions about traditional food ways and modern industrial food ways (i.e., how far does the food that we eat travel to get to our plates) - Participants will actively share this new knowledge with others in their communities 	<ul style="list-style-type: none"> - Participants will be empowered to take care of their health, have autonomy over their own bodies, and make informed decisions about their food choices - There will be an increased use of traditional and healthy foods in diets, with a decreased use of unhealthy foods - Participants will have improved physical health (self-reported) - Participants will experienced reduced reliance on Western medicines (when

Outputs	Outcomes (Intended Impacts)		
Health Circle (Activities)	Short-Term	Intermediate	Long-Term
	<ul style="list-style-type: none"> - Participants will have an enhanced understanding of the relationship between food, body, and mental/emotional wellness 		applicable)
<p>Health Circle 4: Responsibility—Emotional Competence & Wellness</p> <ul style="list-style-type: none"> - Interactive and interpersonal activities - Incorporating teachings into health and wellness strategies 	<ul style="list-style-type: none"> - Participants will gain knowledge about emotional competency, including mental and emotional health - Participants will gain an understanding of how emotional health impacts our physical, mental, and spiritual health - Participants will have increased knowledge of emotional competency, mental health, and wellness - Participants will have increased awareness of their mind and body - Participants will have increased knowledge of strategies for promoting emotional wellness, and how it may impact their holistic health - Participants will have a deeper understanding of the importance of “nonviolent communication” or clearly communicating emotions and needs 	<ul style="list-style-type: none"> - Participants will have improved communication skills and will be able to use “nonviolent communication” to clearly communicate their emotions and needs - Participants will have the ability to actively promote and maintain their emotional and mental wellness - Participants will actively share this new knowledge with others in their communities 	<ul style="list-style-type: none"> - Participants will have improved emotional and mental wellness
<p>Health Circle 5: Reciprocity—Physical Body (external) Medicine Making</p> <ul style="list-style-type: none"> - Gathering at the UBC Farm - Medicine walks - Learning about Indigenous medicines - Feast 	<ul style="list-style-type: none"> - Participants will learn about specific indigenous plants and their connection to health and wellness - Participants will gain knowledge about where medicinal plants grow/can be harvested - Participants will gain skills through the “doctrine of signatures” and other accessible traditional methods of plant identification - Participants will understand 	<ul style="list-style-type: none"> - Participants will be able to identify and practise physical activities for improving and maintaining their emotional/mental wellness - There will be an increased use of Indigenous medicines for maintaining health - Participants will actively share this new 	<ul style="list-style-type: none"> - Participants will be empowered to take care of their health, have autonomy over their own bodies and healthcare decisions - Participants will have increased access to traditional medicines - Through using preventative health practices, there will be a reduced

Outputs	Outcomes (Intended Impacts)		
Health Circle (Activities)	Short-Term	Intermediate	Long-Term
	the link between knowledge of Indigenous medicine and having autonomy over their healthcare - Participants will gain an understanding of the role of reciprocity in holistic wellness	knowledge with others in their communities	prevalence of participants who primarily seek healthcare for emergencies
Health Circle 6: Cultural Competency—Drumming Circle - Drumming circle - Smudge - Invitations to attend weekly drumming circles	- Participants will have increased knowledge of singing and drumming practices - Participants will understand the spiritual significance of singing and drumming, and how they connect to and promote health and holistic wellness	- Participants will have increased confidence and knowledge of songs - Participants will be able to identify community resources that will help them in achieving and maintaining holistic wellness - Participants will be able to use the drum and songs in their personal wellness	- Participants will have enhanced spiritual wellness - Participants will actively share this new knowledge with others in their communities
Health Circle 7: Ceremony and Reciprocity - Witnessing - Teachings around reciprocity (give-away) - Pipe ceremony - Closing feast - Honouring the participants - Opportunity to attend ceremony at a later date (e.g., Yuwipi)	- Participants will gain knowledge about traditional practices and ceremony - Participants will gain new skills and knowledge of how to feel safe and comfortable when looking to participate in ceremony - Participants will have an understanding of where different ceremonial practices come from - Participants will understand the differences in protocol that may be expected when attending ceremony	- Participants will identify healthy role models, cultural practices, and resources that will positively impact their holistic health and wellness - Participants will feel comfortable when they choose to experience ceremony - Participants will have increased connections to community resources - Participants will actively share this new knowledge with others in their communities	- Participants will have enhanced spiritual wellness - There will be increased access to spiritual practices and opportunities to attend ceremony

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The First Nations Health Authority is the first province-wide health authority of its kind in Canada.

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This First Nations Health Governance Structure emerged after many years of First Nations community leadership in British Columbia gathering together and taking decisions to move forward with the creation of a new health system that would deliver former federally designed services.

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Services are largely focused on health promotion and disease prevention and include:

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- Mental Health and Substance Use Programming
- Environmental Health and Research
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First Nations Health Authority
Health through wellness



First Nations
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RESEARCH, KNOWLEDGE EXCHANGE, AND EVALUATION AT THE FIRST NATIONS HEALTH AUTHORITY

The First Nations Health Authority promotes and engages in appropriate ways of gathering and sharing knowledge to inform decision-making and planning that results in the highest level of health and wellness among First Nations individuals and communities in BC.

We acknowledge First Nations Peoples' experiences with research have not always been positive. However, the FNHA along with many First Nations researchers, health service partners and individuals are taking control of their own research to ensure it is beneficial and meaningful to First Nations and their communities.

To ensure research integrates the values and ethics of BC First Nations, research must be carried out in accordance with the 7 Directives developed by BC First Nations as standards for the First Nations Health Governance Structure in BC.

By **RESEARCH**, we refer to a holistic understanding of knowledge gathering and sharing, as a journey of coming to know something more through observing, experiencing, and interpreting. Keeping First Nations decision-making and control at the centre of research, knowledge exchange throughout all stages of a project is an essential component of research.

KNOWLEDGE EXCHANGE refers to the two-way sharing of information between researchers and communities, with the aim to ensure that knowledge generated improves programs, services, policy, or any other information needs identified by communities.

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Some of our work includes:

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- Collaborating on national projects, such as the Regional Health Survey (RHS) and the First Nations Regional Early Childhood, Education and Employment Survey (FNREEES)
- Performing FNHA program and service evaluations for quality improvement purposes

To get involved or for more information, please visit us online: fnha.ca or contact us: rkee@fnha.ca

“When you follow your heart, you provide that path for others”: Indigenous Models of Youth Leadership in HIV Prevention

Abstract

Cultivating and supporting Indigenous peer youth leaders should be an important part of Canada’s response to HIV. This paper examines how a group of Indigenous youth leaders took up the notion of leadership in the context of HIV prevention. Taking Action II was a community-based participatory action research project. Eighteen Indigenous youth leaders from across Canada were invited to share narratives about their passion for HIV prevention through digital storytelling. One-on-one semi-structured interviews were conducted with participants after they developed their digital stories, and then again several months later. A thematic analysis of the interviews was conducted to identify major themes. Youth identified qualities of an Indigenous youth leader as being confident, trustworthy, willing to listen, humble, patient, dedicated, resilient, and healthy. A number of key examples and challenges of youth leadership were also discussed. In contrast to individualized mainstream ideals, Indigenous youth in our study viewed leadership as deeply connected to relationships with family, community, history, legacies, and communal health.

Keywords

Indigenous, HIV, youth, leadership, community-based participatory research, digital storytelling, Canada

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Introduction

In the time of the Seventh Fire a Osh-ki-bi-ma-di-zeeg’ (New People) will emerge. They will retrace their steps to find what was left by the trail. (Benton-Banai, 1988, p. 91)

As described by the Seven Fires prophecy of the Anishinabe¹ oral tradition, the seventh generation is currently upon us (Benton-Banai, 1988; Bergstrom, Miller Cleary, & Peacock, 2003; Monchalín, 2016). It represents a time of Indigenous youth leadership, in which youth will retrace their steps to restore balance among our Nations (Bergstrom et al., 2003). While each individual plays a vital role within Indigenous communities, youth are responsible for “doing the work of the people” (Anderson, 2011, p. 10). The beginning of this paper is influenced by Anishinabe teachings from the ancestry of the first author; it sets the stage for what it means to do Indigenous health research in a decolonizing context. For us, it means situating our work within Indigenous frameworks, teachings, and ways of knowing.²

According to the UN, “youth is best understood as a period of transition from the dependence of childhood to adulthood’s independence. ...The United Nations, for statistical purposes, defines ‘youth’ as those persons between the ages of 15 and 24 years” (UNDESA, 2013, p. 1). A recent UNAIDS report (2010) states that, globally, “young people are leading the

¹ For the purposes of this paper, the spelling of *Anishinabe* will follow Benton-Banai (1988). It is important to note, however, that individuals and communities may spell this word differently, depending on their personal and/or communal preference and/or geography. These alternate spellings may include *Anishinaabe*, *Anishinabek*, *Anishnaabe*, *Anishnabe*, and *Nishnaabeg* (A. Judge, personal communication, February 7, 2016).

² The lead author is an Indigenous youth participant of the project, as well as a community-based researcher currently pursuing her PhD. Being an Anishinabe woman, her teachings on the Seven Fires prophecy have guided and informed this paper.

prevention revolution by taking action to protect themselves from HIV ... [as a result], HIV prevalence among young people is falling in 16 of the 21 countries most affected by HIV” (p. 3). The UN attributes these changes to a heavy investment in youth leadership and capacity building.

In Canada, HIV is on the rise among Indigenous youth, with rates of new infections currently at 7 times that of non-Indigenous youth (Ning & Wilson, 2012). Between 1998 and 2012, just under one third (31.6%) of HIV diagnoses among Indigenous people in Canada were among youth ages 15 to 29 (Public Health Agency of Canada, 2014). Yet models of promoting Indigenous youth leadership are noticeably absent in the literature (Crooks, Chiodo, Thomas, & Hughes, 2009).

Behaviours such as intravenous drug use play a large role in the HIV epidemic, yet determinants of health unique to Indigenous youth must be considered (Flicker, Larkin, et al., 2008; Loppie Reading & Wien, 2009; Public Health Agency of Canada, 2014). For instance, although Indigenous youth are diverse in terms of culture, language, social and geographical locations, they share the legacies of colonialism and its ongoing harmful impacts (Flicker et al., 2013, 2014; Flicker, Larkin, et al., 2008; Oliver et al., 2015). Many Indigenous youth link colonialism, including ongoing effects of residential schools, such as substance abuse and sexual abuse, to HIV in their communities (Flicker & Danforth, 2012). The Royal Commission on Aboriginal Peoples (RCAP) reported that Indigenous youth are paying the price for cultural genocide, racism, poverty, and colonial policy (RCAP, 1996). According to the Seven Fires prophecy, “The task of the New People will not be easy ... If the New People will remain strong in their quest, the Waterdrum of the Midewiwin Lodge will again sound its voice” (Benton-Banai, 1988, p. 93).

Supporting Indigenous youth models of HIV leadership may be an important part of reversing high rates of HIV (National Aboriginal Youth Council on HIV & AIDS, 2010). RCAP (1996) recommended that all branches of government pursue goals of developing and implementing a Canada-wide policy for Indigenous youth “participation at all levels, leadership development, economic development and cultural rebirth, youth involvement in nation building, and cultural and spiritual development” (para. 4.4.9). Similarly, the report of the Standing Senate Committee on Aboriginal Peoples called for Indigenous youth leadership and involvement (Chalifoux & Johnson, 2003). Although policy continues to theoretically affirm the importance of Indigenous youth participation in decision making, little has been written (or done) about its implementation, or towards understanding the nuances and meanings of leadership in an Indigenous youth context.

This paper explores how a group of Indigenous youth leaders, who participated in a community-based participatory action research project, Taking Action II (Danforth & Flicker, 2014), took up the notion of leadership in the context of HIV prevention. Here, we are purposefully inserting the language of action into the common nomenclature of community-

based participatory research (Minkler and Wallerstein, 2003), as a gesture towards reminding others and ourselves that the end goal of our project was to have meaningful action and social change.

Indigenous Youth Leadership in the Literature

Investing in youth engagement and supporting youth leadership represent “a strong protective factor against a host of negative outcomes” and has been associated with positive “widespread ripple effects” (Crooks et al., 2009, p. 13). In the context of HIV, youth leaders can inspire other youth through HIV prevention, peer-to-peer modelling, and setting positive examples in their communities (Kahn, Hewes, & Ali, 2009; Pearlman, Camberg, Wallace, Symons, & Finison, 2002). Moreover, as youth are often more open to change and new ideas than adults, supporting youth leadership may be critical to communal innovation and social change (Kahn et al., 2009). Through discussions with Indigenous youth, Matthew (2009) found that supporting youth leadership can promote resilience, build on current personal strengths, enhance physical and emotional health, improve youth programming, and promote youth commitment to programs by enhancing youth involvement in decision-making processes affecting them.

There is a dearth of literature that interrogates Indigenous models of youth leadership, especially written by Indigenous youth. Existing literature predominantly focuses on the challenges of engaging youth in leadership, emphasizing barriers such as lack of support, tokenism, being silenced in decisions affecting them, stereotypes, intergenerational trauma, and a lack of financial support (Matthew, 2009). Public discourses (i.e., academia, social services, and public health) regularly paint youth as rebellious, unmanageable risk takers (Macneil, 2006). Indigenous youth in particular are often portrayed as “dangerous” and “reckless” (Riecken et al., 2006). Consequently, adults often engage in “adultism,” in which they assume power over youth (Tate & Copas, 2003, p. 41) thereby denying young people’s agency to create change. This discrimination has led to the suppression and underestimation of Indigenous youth’s capacities, skills, and talents by the mainstream public and the academic research community (Checkoway & Richards-Schuster, 2004).

Literature that examines Indigenous adult leadership models often focuses narrowly on those in positions of mainstream conventional power, such as chiefs or tribal councils (Buchanan & Blue Quills First Nations College, 2010). This focus is largely due to colonial interventions such as the Indian Act, which enforced Western notions of leadership and governance (Cote-Meek, Dokis-Ranney, Lavallee, & Wemigwans, 2012). These legal arrangements were designed to undermine, divide, and assimilate Indigenous people and their traditional models (often non-hierarchical/non-patriarchal) of leadership (Alfred, 1999; Monchalin, 2016). Moreover, within a traditional Indigenous paradigm that honours the interconnections of all elements of the community, focusing on a single element (e.g., adults) without understanding its role in maintaining the well-being of all is considered unwise. According to Alfred (1999):

Communities cannot do what is right for the next generation without involving [youth] ... where the link between the young people and leaders is broken, a future negotiated only by politicians and elders will last only as long as those people stay in control. Then who will lead the communities? (p. 130)

Methods

The Taking Action project involved a group of community activists and university-based researchers and students who came together to think about and develop decolonizing approaches and new methods to respond to the elevated rates of HIV in Indigenous communities (Danforth & Flicker, 2014; Flicker & Danforth, 2012). Decolonizing approaches are about changing focus, “centering our [Indigenous] concerns and worldviews and coming to know and understand theory and research from our own perspectives and for our own purposes” (Smith, 1999, p. 39). This community-based participatory action research project was guided by the National Aboriginal Youth Council on HIV and AIDS and adhered to their guidelines for research related to HIV, sexually transmitted and blood borne infections (STBBIs), sexual health, and harm reduction (National Aboriginal Youth Council on HIV and AIDS, 2010). The Native Youth Sexual Health Network, an organization of and for Indigenous youth that works across issues of sexual and reproductive health, rights and justice throughout the United States and Canada, led the project. Community based participatory research (CBPR) continues to be recognized as an effective strategy for working on health related issues with Indigenous Peoples and other marginalized populations (Darroch & Giles, 2014), According to Minkler and Wallerstein (2003):

Community-based participatory research (CBPR) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change. (p. 31)

In the first 3 years of the project (2007-2010), we collaborated with over 100 youth in six different communities on developing art that examined the relationship between structural inequalities and HIV (Flicker & Danforth, 2012). In their evaluations, youth asked for more opportunities to come together with their peers from different communities to learn from each other. As a result, Taking Action II invited 18 Indigenous youth leaders from across Canada to a week-long retreat in Toronto in the summer of 2012 to create digital stories about their interest and involvement in HIV prevention. The goal was to allow youth leaders to share their own digital stories about HIV leadership, activism, and engagement (Danforth & Flicker, 2014; Wilson et al., in press.).

“Digital stories are 3-5 minute visual narratives that synthesize images, video, audio recordings of voice and music, and text to create compelling accounts of experience” (Gubrium, 2009, p. 186). Digital storytelling projects are increasingly being used in public health practice and as part of community-based participatory research (Gubrium, Hall & Flicker, 2014). They fit particularly well within a decolonization framework, which seeks to challenge “the power relations that govern who can speak, what they can say, and how they can say it” (Adelson & Olding, 2013, para. 7). As such, digital storytelling has the potential to respond to Smith’s call for decolonizing research by (re)claiming, remembering, representing, reframing, creating, and sharing (Smith, 1999). In this project, we engaged Indigenous youth leaders in digital storytelling as both a decolonizing approach to research and a public health intervention, which created space for imagining new possibilities for Indigenizing HIV prevention with youth.

Twenty Indigenous youth leaders were selected from across Canada. Eighteen youth were able to participate in all aspects of the project, while two left the project early for personal reasons. Youth were from a mix of First Nations, Métis, and Inuit communities, rural areas, and urban contexts. They hailed from eight different provinces and one of the territories. At recruitment, youth ranged from 16 to 26 years old. There were seven male and 11 female youth leaders.

Youth leaders were recruited to a week-long retreat in Toronto through a call-out via social media and online outlets (i.e., listservs, Youtube, Facebook, Twitter). Personal networks were also tapped to encourage leaders to apply. Recruitment materials purposefully defined leadership broadly and provided the following examples:

Have you ever been part of an event about: HIV, drugs, poverty, human rights, justice, Aboriginal rights, sexual health, or violence? A volunteer or peer outreach worker? ... A helper or organizer of a workshop, event, or fundraiser about HIV? ... Part of any effort to spread the word about HIV? We are seeking motivated, passionate and energetic Aboriginal youth to share their stories about HIV leadership or activism ...

Leaders were selected based on their interest or involvement in HIV prevention, engagement, and activism. Two of the selected youth identified as being HIV positive; others were affected in multiple ways. Youth were selected to reflect the diversity within Indigenous communities (e.g., Nation, gender, HIV experience), capture multiple experiences, and understand various ways that youth have engaged in the HIV movement. Once youth had accepted our invitation, they were supported in preparing their digital story in which they shared their personal journey. Four months prior to their arrival in Toronto, youth were provided with the appropriate tools for collecting images, sound clips, and videos to use in their story; they also participated in regular teleconference calls in preparation for the retreat. The digital storytelling retreat was conducted on York University’s campus and made use of the Faculty of

Environmental Studies’ computer lab and other facilities. Youth were provided guidance and support by project facilitators and their peers in putting together their digital stories (Danforth & Flicker, 2014). In order to create their own digital stories, youth worked in groups and individually to develop and refine their narratives, record them, and then enhance the audio with pictures and video. Youth learned how to use video-editing software to compile and edit their audiovisual material and complete a final product. In some cases, youth staged and filmed new material. Often these processes were iterative rather than linear. Youth were both learning about and applying their new knowledge in a number of different areas at the same time. At the end of the week, we held a private screening where each youth got to share their final story with the group. For many youth participants, this process involved difficult intellectual and emotional work. However, nearly all found it rewarding.

Youth leader participants were provided with training, support, and resources during all stages of the project. This support included creating a sense of community and safe environment to explore what are sometimes difficult issues. Part of decolonizing the research process meant embedding Indigenous practices and ceremony into the project programming. For example, access to art and beadwork supplies, smudging (a purification ceremony involving the burning of one or more of the four sacred medicines so that the smoke can do its cleansing work; Monchalin, 2016)), and cultural support were all regular features. In addition, different youth took turns leading/sharing their own traditional songs and ceremonies. In recognizing that these Indigenous youth leaders were being called upon to do “heavy work,” it was important to break up the retreat with activities that were fun and supported relationship building. These activities included shopping and movie excursions into the city, as well as visiting a nearby First Nations community to learn about their sexual health initiatives.

Data Collection

Once youth leaders developed their digital stories, one-on-one semi-structured interviews were conducted with them. Youth were asked to introduce themselves and their community, tell us about their digital stories, discuss their feelings about being Indigenous, share what being a “youth leader” means to them and provide examples, and reflect on the retreat itself.

Subsequently, the youth were supported in screening their digital stories within their respective communities. Shortly after their community screenings, another semi-structured interview was completed either via telephone or in person. The second interview provided youth with an opportunity to reflect on a concrete example of their leadership (organizing and presenting their screening) and how it felt to share their stories more publicly.

Interviews were transcribed verbatim. A small subset of investigators, graduate students, and Indigenous youth reviewed the transcripts and developed a coding framework that represented both inductive and deductive themes emerging from the transcripts; data were coded by at least two research assistants and managed in QSR NVIVO 10. Data for this paper were drawn from all the leadership codes (e.g., What Leadership Means, Support for Leaders, Who

Am I, Educating Others, Changing My Path, Living in a Good Way, Connections to Land, Family, Community, Self, etc.). All of the leadership codes were reread, re-analyzed, and re-organized, and an inductive thematic analysis (Vaismoradi, Turunen, & Bondas, 2013) was conducted to find patterns and trends (within themes analyzed). Three overarching themes emerged: qualities of a leader, challenges of being a leader, and examples of demonstrating leadership. Using MS Word, summary quote tables were created with named subheadings to help organize the findings; these tables became the framework for this paper.

We engaged in a form of participatory “member checking” 1 year later at a follow-up retreat with the youth leaders in July 2013. We invited participating youth to come together again in Montreal for a weekend to engage in participatory analysis. Youth came together to review and reach consensus about themes, quotes, and key ideas as well as provide feedback on preliminary analyses. In general, the youth were very proud of one another’s accomplishments, definitions, and leadership initiatives.

Each youth received a \$1,000 honorarium (spread over 3 years) for their substantial contribution to the project. In addition, they received a \$20 honorarium per conference call, and all travel and accommodation costs were covered for both retreats. Each youth leader managed a \$500 budget to defray costs associated with the “movie nights” in their communities. Project facilitators were present for each of the movie nights and provided ongoing support and assistance with logistics and implementation.

Results

Although the youth were diverse in terms of culture and geographical locations, they shared many similar ideas surrounding leadership in the context of HIV prevention. Drawing on the interviews, three main themes emerged regarding HIV leadership: qualities of a leader, challenges of being a leader, and examples of demonstrating leadership. Grounded in a critical social science perspective (Eakin, Robertson, Poland, Coburn, & Edwards, 1996), these themes are explored below, with quotes from the youth leaders provided in tabular format.

Qualities of a Leader

Leadership qualities identified by youth participants included being confident, trustworthy, willing to listen, humble, patient, dedicated, resilient, and healthy (see Table 1).

Table 1

Qualities of a Leader, as Defined by Indigenous Youth Leaders

Confident	“Being a leader generally means you know that you are not afraid to take the steps accomplishing your goals.” (Female) “A leader is someone who is not afraid to lead the way, to be the first one. To do something. To explore something.” (Male)
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<i>Qualities of a Leader, as Defined by Indigenous Youth Leaders</i>	
Trustworthy	<p>“Doing the work with the people that trust in you and believe in you or even would put their life in your hands. You would have to work with them and show them that you are actually caring.” (Male)</p> <p>“Leadership means that there is a person that stands out for the people. They help people that need help. They do stuff for people when someone needs something done.” (Male)</p>
Willing to listen	<p>“It is also someone who steps back and listens to the needs of everybody else ... it’s someone who can take initiative, who can listen and with their heart, their mind, with everything to, I guess, start the movement.” (Female)</p> <p>“A lot of people have this image that leaders are the ones that are talking, but I feel a lot of leaders, youth leaders, are the ones listening ... being able to support people even though they may not be necessarily supported in their decisions.” (Female)</p>
Humble	<p>“It’s not about having that title of leadership ... you are out there to make a difference, you are out there to work with one person at a time, to work with another person, and to build a community that is solid.” (Female)</p>
Patient	<p>“Being a leader also means being patient ... you know that it means it’s not going to happen overnight.” (Female)</p>
Dedicated	<p>“Being a leader, you have to have a plan, you have to have a destination or a goal that you are after.” (Male)</p> <p>“You got to be dedicated to the change that you want to see in your communities and it’s not going to be easy. But if you really believe in something then you are going to continue to get back up and keep working towards different approaches.” (Male)</p>
Resilient	<p>“He realized he was in a bad environment and he wanted to change it for himself.” (Male)</p> <p>“Our youth are so resilient and so inspirational that we have found our strengths within each other and created our own community within ourselves to support each other.” (Female)</p>
Healthy	<p>“Know and understand that it’s okay to take a step back sometimes to just take care of yourself. Because if you can’t take care of yourself then you can’t help anyone else.” (Female)</p>

Confidence was understood to be a key attribute of a leader. The youth defined confidence as “not being afraid to lead the way,” to take action in their communities, and to accomplish their goals.

Youth believed trustworthiness is also an important quality of a leader in the HIV movement. Given the high degree of HIV stigma in their communities, youth felt that a leader needs to be someone that individuals can rely on and trust in the face of adversity.

Youth asserted that leaders are individuals who listen to the needs of their communities. Rather than making decisions unilaterally, a leader is someone who listens, and who serves the community’s needs. The youth described how a good leader is not necessarily someone who is looking for a leadership title. Rather, the focus of a leader should be on things that benefit the community, rather than themselves. As a result, they felt humility is also an important characteristic of a strong Indigenous leader.

Many of the youth noted the struggles and barriers associated with substance use in their communities. They described a leader as someone who is able to make the decision of living a good life without substance abuse (or who actively tries to recover from an addiction). They further stated that a leader is someone who strives to be physically, mentally, and spiritually healthy. Youth leaders emphasized that leaders must remember to take care of themselves if they are going to be able to take care of their communities.

Challenges of Being a Leader

The youth described many barriers they regularly face within their communities when they, themselves, or their peers try to take on a leadership role. These challenges to leadership were as follows: being a young population, a lack of role models in their communities, tokenism, intergenerational trauma, HIV stigma, and pressure to succeed (see Table 2).

Table 2
Challenges of Being a Leader, According to Indigenous Youth Leaders

Young population	“We have a younger, a very young, up and coming population. If these youth are not being brought up with good mentors, whether it’s their parents, or whether it’s somebody else teaching them in the community, then where do they go and what do they do? ... It really, really hurts because I know so many young people who are trying the best that they can and people look at them and it’s just so easy to look down on them when they don’t know the struggles ...” (Female)
Lack of role models	“We don’t got too many leaders on the reserve in our community.” (Male) “In my community you don’t see a lot of Aboriginal people graduating.” (Female)
Tokenism	“I feel a little bit upset sometimes when our leaders utilize our youth as the reason why they are doing things yet they don’t really include us ... we feel that we are not being supported by the people who claim to be our leaders.” (Female)

<i>Challenges of Being a Leader, According to Indigenous Youth Leaders</i>	
Intergenerational trauma	<p>“We still face the legacy of the residential schools to this day, and the things that happened to our grandparents, great-grandparents, even sometimes our parents ... residential school has kind of trickled down by generations.” (Female)</p> <p>“There is a lot of healing that needs to still take place ... and unfortunately there are still a lot of people who are healing in our communities.” (Female)</p>
Stigma	<p>“It can be tough because some people ... don’t want to believe it or they just don’t want to listen, and, or maybe some parents might think, ‘I am teaching my children the way I want them to be taught’ kind of thing, ‘I don’t want anyone else to teach them about HIV/AIDS because that leads to sex or drugs or whatnot.’ They take it the wrong way.” (Female)</p>
Pressure	<p>“It is the pressure of always having, the feeling of always having to be strong, to look strong for others ... you will have that weight pushing down on you while you lead.” (Male)</p>

Almost half of the Indigenous population in Canada is under the age of 24 (Statistics Canada, 2011a). This skewed demographic was reflected in the youth’s responses to the question of challenges to leadership. Youth believed that they lacked positive mentors, role models, and young leaders within their communities. Specifically, they described widespread apathy and a lack of motivation and ambition to finish school among their peers. Youth believed that leaders within their communities were individuals who graduated from either high school or postsecondary school.

Many youth felt they experienced tokenism. This meant that although they were often asked to participate on committees or represent youth issues, they were rarely treated equally, and (diverse) youth voices continued to be underrepresented. Youth reported that they seldom had support to fully participate as decision makers, and they were often excluded from important conversations.

A major challenge to the development of leadership discussed among these youth was intergenerational trauma, which is defined as cumulative emotional and psychological wounding across generations (Blanchet-Cohen, McMillan, & Greenwood, 2011; Lavalée & Poole, 2009). Youth stated that they continued to face intergenerational trauma due to the legacy of residential schools in their communities. They believed that this was a major challenge to becoming a leader because there was a lot of healing that needed to take place both internally as individuals, and within their communities.

Another challenge to being a leader was stigma and discrimination associated with HIV. When youth tried to educate others in their communities about HIV, they often received a

negative response. Some parents believed that education would lead to increased sexual activity and substance use. Other youth discussed how, because of the stigma, members of their communities denied the existence of HIV.

Lastly, due to the history of Indigenous communities in Canada marginalizing their own people with HIV and a general lack of discussion about HIV in communities (Vizina, 2005), the youth leaders of this project felt a lot of pressure to succeed in their efforts to challenge stigma. The high rates of stigma around HIV within many Indigenous communities in Canada have resulted in some HIV-positive Indigenous community members being shunned or treated poorly because of their health status (Lesperance, Allan, Monchalín, & Williams, 2015; National Aboriginal Youth Council on HIV & AIDS, 2015; Restoule, Campbell McGee, Flicker, Larkin, & Smillie-Adjarkwa, 2010; Worthington et al., 2010). This situation has created a sense of urgency for youth leaders to educate their community to overcome stigma.

Demonstrating Leadership

Despite multiple challenges, the Indigenous youth in this project continued to take action and demonstrate leadership in a variety of ways. Common themes regarding how they enact Indigenous models of leadership included starting small, getting an education, mobilizing community, teaching others, and preserving culture (see Table 3).

Table 3

Demonstrating Leadership, as Described by Indigenous Youth Leaders

Starting small	<p>“Being a leader starts in the most smallest and intimate places ... I try to be a good role model ... for my brothers and my sisters and my cousins. And that’s initially where I guess being a leader starts, is in your family.” (Female)</p> <p>“We need to start in our community and where we live... we are having issues, too many to deal with. So we need to work on ourselves before we can work outside.” (Female)</p>
Getting an education	<p>“I was graduating for all Aboriginal people and I guess all of my community, and all of my family. You know, it was just like this big stepping stone. A bigger place.” (Female)</p>
Mobilizing community	<p>“I really try to spend most of my time trying to like mobilize community, my poor community has had to deal with so many events. But it’s like a really big part of me, teaching educating people, just because that’s just something that I always loved to do.” (Female)</p>

<i>Demonstrating Leadership, as Described by Indigenous Youth Leaders</i>	
Teaching others	<p>“By educating myself more in HIV and AIDS, I can discreetly educate other people and ... that may spark something inside of them, some inspiration where they might want to do difference and change things.” (Female)</p> <p>“When I go back home, that’s what I am going to be trying to do ... educating people more towards how to support other people and to how we can work together to break down the barriers.” (Male)</p>
Preserving culture	<p>“If I can help somebody grow or help them find an opportunity or to even be there just to have a conversation with them, then I know that I am doing what my ancestors would like me to do. And that’s just following my heart. ’Cause when you follow your heart you provide that path for others to follow your lead, and I think that that’s what a lot of our young people and a lot of our people are doing ’cause we are following our heart back to that remembering of who we are as Indigenous people.” (Female)</p>

Youth highlighted the importance of a leader’s “starting small.” For them, this meant being a role model for their friends, family members, and community. Youth stated that a leader is someone who works to establish strong ties in their family unit and communities before venturing outside their personal networks. Many provided examples of slowly expanding their influence by being active on youth councils and committees in their schools and communities. One explanation for this understanding might come from the teaching that everyone in a community carries responsibility for the whole; this interdependency is crucial to an Indigenous understanding of communal health (Anderson, 2011).

Youth noted the importance of educational achievement as an example of how they demonstrate leadership. When they spoke about education, the youth talked about finishing high school and pursuing postsecondary education, such as college or university. Youth participants believed that when they graduate, they are doing it for their entire community. Completing high school is a particularly important accomplishment in the context of current low graduation rates within many Indigenous communities across Canada. For example, only 9.8% of Indigenous people aged 25 to 64 have a university degree, compared to 26.5% of non-Indigenous people in Canada of the same age group (Statistics Canada, 2011b). Thus, education was not understood as merely an individual achievement, but a community achievement.

The youth talked about their experiences of participating in this project as an opportunity to teach others within their communities. Prior to and during the Toronto retreat for the Taking Action II project, youth did research on HIV and AIDS to assist with developing their digital stories. Youth stated that by educating themselves further about HIV, they were better able to educate their communities. Many youth shared plans for being HIV peer-educators “back home.”

This role involved educating others about how to better support one another. Several youth talked with excitement about how showing their digital stories sparked important dialogue around the topic of HIV prevention.

Most notably, during conversations around leadership, youth returned to the importance of their ancestors and culture. Many youth believed that demonstrating leadership in their communities means preserving culture, and remembering who they are as Indigenous people. This meant different things for each youth; for instance, for one youth this meant “following your heart.” Wilson et al. (n.d.) support this notion and state that culture, community, history, and tradition are essential for effective HIV prevention and health-promotion initiatives for Indigenous youth.

Discussion

Although the Indigenous youth participants in this study were diverse in regards to Nation, location, and culture, common themes emerged in defining models of leadership in the context of HIV prevention. Notably, participants privileged qualities of Indigenous leadership (e.g., humility, patience, trustworthiness, resilience, and health), which contrast mainstream hierarchical notions of power, status, and individualism (Buchanan & Blue Quills First Nations College, 2010; Monchalin, 2016; Ottmann, 2002, 2005; Stonefish, 2013).

Participants’ views about leadership echoed much of the literature on Indigenous perceptions of leadership. These perceptions included focusing on and responding to community (Ottmann, 2005), being resilient (Crooks et al., 2009; Julien, Wright, & Zinni, 2010), preserving culture (Ottmann, 2002), mobilizing others (Buchanan & Blue Quills First Nations College, 2010), being honest, and showing confidence (Muskego, 1995). Nonetheless, much of the literature examining Indigenous leadership models continues to perpetuate mainstream hegemonic concepts of leadership and focuses narrowly on those in positions of conventional power imposed by colonial interventions, such as the Indian Act (Buchanan & Blue Quills First Nations College, 2010; Ottmann, 2002, 2005). The Indigenous youth leaders in our study did not openly strive for the titles associated with leadership; instead, many felt it was important to lead by listening. Alfred (1999) describes this as the ability to lead by being led.

Indigenous youth strategies for reversing the negative trends of HIV in their communities involved educating themselves, teaching others, mobilizing community, and starting within their families and intimate social networks. Their ideas demonstrate a holistic understanding of leadership. Holism can be viewed as sustaining a balance, and recognizing “our interconnectedness to everything in the world, and to living in harmony with all of creation” (Monchalin, 2016, p. 34). Moreover, Anderson (2011) argues that the ways in which Indigenous communities are holistically interconnected across generations are “critical to the health and well-being of the present-day and future community” (p. 168). This concept of holism speaks to youth notions of leadership as the connection of family, community, and culture.

Many youth noted the importance of education as an example of how they demonstrate leadership. For youth, education meant finishing high school and pursuing postsecondary education such as college or university. Despite a long history of educational assimilation in Canada, which has led to ambivalent attitudes toward formal education among many Indigenous people, young Indigenous people (and their parents) aspire to attain ever higher levels of education (Hudson, 2009; Restoule, 2005; Restoule et al., 2013). According to Stonechild (2006), “education is truly the new buffalo” (p. 1). In the past, the buffalo met virtually every need with regards to food and shelter, and it was considered a gift from the Creator (Stonechild, 2006). According to Stonechild (2006), some Elders now claim that education, like the buffalo, is necessary for survival (Restoule, 2005) and should be supported alongside cultural and environmental teachings.

In their responses, many of the youth in this project focused on the challenges and barriers that young Indigenous people experience. The most prominent of these is the impact of intergenerational trauma caused by residential schools, which operated in Canada from 1831 to 1996 (Kelly, 2008). Anderson (2011) provides a circular model entitled “Social Organization of ‘Traditional’ Communities,” demonstrating the roles undertaken within an Anishinabe community that was promoting community health and well-being. In the diagram, youth are the heart of the circle, surrounded by Elders, women, and men, in that order. Anderson explains that “the circle was blown apart when residential schools ripped the children—the heart—out of the community” (p. 169). Many Indigenous children suffered sexual, mental, and emotional abuse committed by figures of authority and caretakers in the schools (Chavoshi et al., 2012). Generations of former students brought home devastating burdens of unresolved trauma into their communities, perpetuating the cycle of abuse (Chavoshi et al., 2013). As Anderson further articulates, “Alcoholism, depression, and suicide were not long to follow” (p. 170). Youth indicated that there was still a lot of healing that needed to take place in their communities, and that this was a direct barrier to becoming a leader.

Despite the challenges, youth provided many examples of how they were demonstrating leadership, and how our project motivated them to continue to agitate for change. For example, after returning home from the retreat, each participant hosted digital story screening events to promote discussions around HIV in their communities. Many facilitated peer-led, community arts-based programs and sexual health outreach initiatives. They have also spoken at conferences, developed new interventions for their peers, become involved in Idle No More and other social justice causes, and been more engaged in traditional ceremonies. Some have pursued postsecondary education in health studies; others have entered the film and music industry.

Peer educators can “address misconceptions, prejudices, attitudes and stigmas surrounding sexual health” (Sriranganathan et al., 2010, p. 63). The peer-led initiatives youth brought back to their communities illustrate that investing in youth leadership can play an important role in reversing the negative trends of HIV, and improving the overall health of

Indigenous communities. However, to reverse those trends, youth must be met “where they are at” (Native Youth Sexual Health Network, 2013). This means that it is not about “saving” Indigenous youth and imposing conventional disease-control approaches onto them. Rather it is “about creating space for youth to tell us what makes them feel empowered, supporting the self determination they have over their bodies, lives and spaces” (Native Youth Sexual Health Network, 2013). This empowerment can be accomplished through peer education, a health-promotion approach that provides youth the opportunity and safe space to learn about sexual health and ask questions from their peers who will likely understand (Sriranganathan et al., 2010).

Ultimately, supporting youth voices in decision making is a fundamental part of tackling HIV and making positive change within our communities (UNAIDS, 2010). The research team who led this project did just that. The goal of this project was to support and empower Indigenous youth leaders to effect positive change. The examples below demonstrate the support provided by this team, which may function as recommendations for future Indigenous youth leadership support work. The Taking Action II team supported youth leadership in this project through the following:

1. *Training*: During the retreat, youth were provided with training on how to create a digital story through computer video software, including tips on how to record (visually and orally) stories surrounding HIV and Indigenous youth leadership.
2. *Resources*: Youth were given information packages and video cameras 4 months before the Toronto retreat to record footage. Doing so provided youth with the freedom to collect video footage prior to the retreat, and to start conversations within their communities around what they were doing.
3. *A support network*: The Taking Action II team consisted of facilitators and organizers whose primary goal was to support the youth. This support included having a traditional knowledge holder and cultural support person on the team, peer-to-peer support, multiple conference calls, and a safe space for sharing. The research team also supported youth with screening their films within their respective communities, and youth were given an opportunity to share their experiences and reflections in the follow-up Montreal retreat.
4. *Connections*: Youth leaders were provided with the opportunity to connect with various individuals through this project to support their leadership endeavours. These connections included other youth leaders from across the country, community-based organizations affiliated with the project, and researchers within their respective fields of interest. Team members also worked hard to bring youth into their networks and wherever possible, link youth into other projects and events.

5. *Financial support*: Youth were provided an honorarium for each teleconference in which they participated, along with sponsored travel, accommodation, and meals during the Toronto retreat and the follow-up Montreal retreat. In addition to this support, youth were provided financial support to host a movie night within their communities to show their digital stories.
6. *Capacity building*: By providing training, resources, a support network, and connections, the youth have developed their capacity to catalyze leadership within their communities. As reported in the results, youth are motivated to mobilize and teach others in their communities about HIV and AIDS.

Limitations

This study was a first step in unpacking how a select group of self-identified Indigenous youth leaders conceptualized leadership. Although youth were selected from different communities, Nations, and contexts, the sample was not representative of all Indigenous youth in Canada. For example, the voices of two-spirit youth were absent in our sample. Moreover, those who participated did so because they were particularly interested in HIV and/or digital storytelling. Nevertheless, this purposive sample elicited surprisingly consistent views on leadership across individuals from disparate regions and cultures.

This project raises important themes around Indigenous youth leadership that warrant further investigation. Because our sample was small and diverse, we were unable to disaggregate models of leadership by Nation. Further exploration within specific community settings around how Indigenous youth define leadership may raise important distinctions about how to support the diversity of Indigenous youth leaders.

Conclusion

The National Aboriginal Youth Strategy on HIV/AIDS recommends “meaningful Aboriginal youth participation and engagement that provides supportive spaces for Aboriginal youth to share, create strong partnerships, build capacity and skills, and be empowered to influence policy, programming and education about HIV and AIDS” (National Aboriginal Youth Council on HIV & AIDS, 2010, p. 5). Indigenous youth must be treated as equals and be fully immersed in decision-making processes (Matthew, 2009). With the right support, Indigenous youth can be important producers of knowledge (Flicker, Larkin, et al., 2008) and can play active roles as change agents (Flicker, Maley, et al., 2008).

Additionally, according to the Canadian Aboriginal AIDS Network (CAAN), “diversity within the Aboriginal population demands creativity to respectfully engage all of our Peoples in the response to HIV/AIDS,” and adopting a pan-Aboriginal approach may obscure important cultural differences (Masching, 2009, p. 5). An effective response to sexual health education must take into consideration local contexts and diversity. Smylie et al. (2004) further this and state that “successful health research in Aboriginal communities requires community relevance”

(p. 139). Although each youth leader created and showcased a digital story reflecting their own unique community context, this paper clustered the youth’s thoughts around leadership. Further investigation must be undertaken to explore Nation-specific Indigenous youth models of leadership and to learn about the diverse goals, strengths, and aspirations of Indigenous youth across Canada.

Moreover, we suggest further analysis of the intersection of gender and Indigenous youth leadership in the context of HIV, particularly in light of the colonial impact on Indigenous gender roles (Clark, 2012; Cote-Meek et al., 2012). For example, while Indigenous women are taking up more key leadership positions within their communities, they remain underrepresented in decisions that affect them (Lawrence & Anderson, 2005; Voyageur, 2008). Clark (2012) explains that “matriarchal and co-operative societies did not fit within the individualistic and patriarchal ways of the colonizer” (p. 145). Despite this, young females within this project are challenging colonial norms of leadership through demonstration. Brant-Castellano (2009) provides a quote by an Iroquoian chief which emphasizes the importance of equality: “When you go out to gather medicine ... you must be careful to gather both the male and the female, otherwise your medicine will have no power” (p. 206). Further exploration around leadership must support Indigenous youth in fulfilling the Seven Fires prophecy by enabling them to revive equality within their communities. Restoring this balance may be important in eliminating high rates of HIV and in healing communities.

This project demonstrated that youth are producers of knowledge and play active roles as change agents who can influence policy, programming, and education. By investing in youth leadership through appropriate supports and resources, and by supporting Indigenous models of youth leadership, researchers, policymakers, educators, and communities can gain key allies in the fight against HIV.

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Sexy Health Carnival on the Powwow Trail: HIV Prevention by and for Indigenous Youth

Abstract

Background: This article introduces a peer-led pilot intervention called the “Sexy Health Carnival” (SHC) that takes a strengths-based approach to promoting Indigenous youth sexual health in a culturally safe context. **Methods:** In 2014, Indigenous youth leaders brought the SHC to four Ontario, Canada, powwows, where they administered an offline iPad survey to 154 Indigenous youth (aged 16 to 25) who engaged with the SHC. The survey gathered descriptive data on HIV prevention behaviours and intentions, and the acceptability of the SHC approach in powwow settings. **Results:** Over one third (40%) of youth thought that “a lot” of sex happens at powwows; 14% reported that they were either “definitely” or “probably” going to “hook up” or be sexual with someone at the powwow, and another 14% were not sure. Among those contemplating sexual activity, 79% said they would use a condom that they received at the SHC. The majority (80%) of youth rated the SHC as “awesome.” **Conclusion:** This pilot provides preliminary evidence that the SHC is feasible and welcomed by youth in powwow settings. This project illustrates that Indigenous youth are capable of developing successful sexual health outreach and HIV prevention resources for each other.

Keywords

Indigenous, HIV, youth, sexual health, community-based participatory research, peer-led, Ontario, Canada

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Introduction

Powwows are a social and cultural celebration. Whether contest or traditional, contemporary powwows are gatherings that celebrate, reclaim, and maintain local traditions,

ceremonies, and culture. They are meant to be safe and welcoming environments that attract large groups of people from surrounding regions. Those who travel from powwow to powwow and participate through dancing and drumming refer to the journey as being on the “powwow trail.”¹

Powwows are a culturally significant, spiritual, and sacred practice to many Nations across Turtle Island. It is important to recognize that although there are many similarities between powwows, each must be understood within its local context as a product of the unique community’s history (Gilley, 2006; Hoefnagels, 2007). Commonly a blend of ceremonial and social activities, song, dance, and art vendors, powwows are a method of cultural revitalization that strengthens Indigenous people and their identities (Hoefnagels, 2007). Within some Anishnaabe contexts, for example, the spatial arrangements of powwows reflect the spiritual meanings associated with traditional teachings (Hoefnagels, 2007). Powwows may be set up in a circular formation with many layers, with the heart of the powwow being the big drum, which is circled by the dancers, followed by the spectators, and then the vendors. This circular arrangement reflects the cyclical worldview prominent in Anishnabek life and the interrelatedness of the various components of the powwow (Hoefnagels, 2007). Additional examples of cultural significance are the symbolic meanings of the dancers’ outfits, referred to as regalia, for which traditional objects are used to represent one’s unique Nation and culture. Further, each style of dance has its own history. Two (among many) examples are the Jingle Dress Dance, known for its healing properties, and the men’s Traditional, in which movements often reflect connections to the historic warrior societies from which the powwow evolved (Hoefnagels, 2007). Dancing at powwows is understood to help maintain a connection to Mother Earth, one’s ancestors, and the spiritual world (DesJarlait, 1997).

As with any large group of people coming together, the social environment of powwows creates ideal opportunities for what some Indigenous youth call ‘snagging’. This refers to trying to find a date, getting a phone number, finding a partner, or finding someone who might like to have a sexual interaction at or after the powwow. Gilley (2006) notes, “‘Snagging’ is a slang term used ... to reference a casual sexual encounter with someone.” (p. 565). Powwows are often times for people to ‘snag’. “‘Snaggin’ can also mean ‘tipi-creepin,’ which is the act of having sex with [different or] multiple partners over a period of time (i.e. sneaking from tipi to tipi). Each night after the official pow-wow activity ends, there are often impromptu ‘after-parties’, “known as ‘forty-nines’ (49s)” (Brokenleg, 2010, p. 4). Some Indigenous youth who engage in snagging may perceive that since they are in a “safe” Indigenous social context, they are not likely to be susceptible to sexually transmitted infection (STI) transmission (Vernon & Bubar, 2001; Vernon & Jumper-Thurman, 2002; Weaver 1999).

Despite these perceptions, Indigenous youth in Canada experience both HIV (Public Health Agency of Canada, 2010b) and chlamydia (Health Canada, 2011) at a rate *seven times*

¹ On a powwow trail (also known as a powwow circuit), individuals or groups, such as dancers and vendors, travel to a series of powwows over the spring, summer, and fall months. Within specific regions, powwows are typically planned so that they do not overlap with one another. This provides the opportunity for people on the powwow trail to attend each powwow.

higher than non-Indigenous youth. Overall, the rate of STIs reported is 2.5 times higher among Indigenous youth than among their non-Indigenous counterparts (Chavoshi et al., 2012; Public Health Agency of Canada, 2010a; Rotermann, 2005). These numbers are significant because Indigenous youth aged 15 to 24 represent 18.2% of the total Indigenous population, and 5.9% of all youth in Canada (Statistics Canada, 2011).

However, “being Indigenous or being a young person is not a ‘risk factor’ by itself. In fact, being ourselves can be empowering. What actually puts our lives at risk are things like colonialism, racism, and not having access to culturally safe care” (Danforth & Flicker, 2014, p. 7). Although Indigenous youth are “diverse in terms of culture, language, social and geographical locations, they share the legacies of colonialism ... and its ongoing harmful impacts” (Flicker, Larkin, et al., 2008, p. 177). In particular, many Indigenous youth are the children and grandchildren of survivors of the residential school system. These schools, operating from 1831 to 1996, came with the Canadian government’s policy of “aggressive assimilation” (Kelly, 2008, p. 23; Monchalain, 2010). Many Indigenous children suffered as a result of the pervasive sexual abuse committed by figures of authority in the schools.

Generations of former students brought home devastating burdens of unresolved trauma into their communities, perpetuating cycles of violence (Chavoshi et al., 2013). These experiences with sexual abuse led to broken systems for transferring culturally safe sexual knowledge, such as coming of age (or rites of passage) ceremonies, which some communities are currently reclaiming (Yee [Danforth], 2009). As a result of this violence, STI exposure has increased, due in part to the inability to negotiate safer sex because of low self-esteem and experiences of powerlessness (Chavoshi et al., 2013). This is further exacerbated by low rates of condom use, the strong link between substance use and sexual risk taking, and a lack of harm reduction services for Indigenous youth (Anderson, 2002; Chavoshi et al., 2013; Flicker et al., 2013; Public Health Agency of Canada, 2014; Shercliffe et al., 2007). Fear-based education, abstinence promotion, and overall conventional public health and disease-control approaches to sexual health education have been largely unsuccessful at changing these realities (Danforth & Flicker, 2014; Flicker et al., 2013; Gilley, 2006; Leis, 2001; Steenbeek, 2004).

Powwow after-parties may be a facilitator of sexual interactions. As a result, powwows present a unique opportunity to promote culturally safe, positive sexual health behaviours. Cultural safety is defined as approaches that move “beyond the concept of cultural sensitivity to analyzing power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to healthcare” (National Aboriginal Health Organization, 2006, p. 1). In this context, culturally safe programming means adopting approaches that acknowledge the complexities of Indigenous youths’ identities and histories and that respect their choices to make informed decisions about their well-being.

This paper describes a peer-led pilot intervention called the “Sexy Health Carnival” (SHC), which takes a strengths-based approach to promoting Indigenous youth sexual health in a culturally safe context.

Background

The National Aboriginal Youth Strategy on HIV and AIDS in Canada “promotes peer education as an effective strategy” (National Aboriginal Youth Council on HIV & AIDS, 2010, p. 5). Youth outreach workers who closely reflect target clients in terms of age, ethnicity, language spoken, and experience have proven to be an effective health promotion approach (Steenbeek, 2004). Blanchet-Cohen, McMillan, & Greenwood (2011) assert that peer-led approaches are beneficial because “peers can relate to other youth more easily. Because of a similarity in age, there is a commonality in lived experience ... Peers know how to communicate information in a way that is heard” (p. 102). Peer educators also benefit from peer education programs themselves because they gain increased knowledge and positive opinions and attitudes around sexual health (Sriranganathan et al., 2010). Moreover, with the right support, Indigenous youth can be important producers of knowledge (Flicker, Larkin, et al., 2008; National Indigenous Youth Council on HIV/AIDS, 2015) and can play active roles as change agents (Flicker, Maley, et al., 2008).

Supporting Indigenous youth in peer-led leadership initiatives around sexual health is a core value of the Native Youth Sexual Health Network (NYSHN). NYSHN is an organization by and for Indigenous youth that works across issues of sexual and reproductive health, rights, and justice (Native Youth Sexual Health Network, 2014a). NYSHN has been doing successful peer-led sexual and reproductive health outreach for several years; one such initiative is the SHC. This Indigenous youth-led project creates a fun and interactive opportunity for other Indigenous youth to become educated about HIV prevention and sexual health (Native Youth Sexual Health Network, 2014b). The term *carnival* was chosen intentionally: By playfully conjuring up images of a travelling circus, it reminds us that learning about our bodies can be entertaining and the teachings can be taken “on the road.”

Created by NYSHN youth facilitator Alexa Lesperance, with the help of her community, Naotkamegwaning First Nation, and support from the NYSHN team, the SHC breaks down the barriers of fear, stigma, and shame related to issues around sexual health. It offers accessible “safer practices” content that makes learning health information more fun and inspiring for youth, community members, parents, grandparents, and Elders. The SHC consists of a collection of informative booths and interactive games. The booths include topics such as suicide, HIV and AIDS, harm reduction, consent, sexual violence prevention, healthy relationships, STIs, birth control, and masturbation. The interactive SHC games include dart balloons, a bean bag toss, wheel of sex trivia, sex-positive button making, an HIV prevention guessing game, photo booth, steps to putting on a condom, and many more. The SHC is also packed with prizes, culturally safe information, and safer sex supplies, as well as content and age-appropriate activities (Native Youth Sexual Health Network, 2014b).

The SHC was developed first and foremost as a peer-to-peer intervention and quickly became a popular program offering of NYSHN. This study grew out of a desire to evaluate its effectiveness and learn more about participants who were engaging with the program at

powwows. The principles of ownership, control, access, and possession (OCAP[®])² guided the research process (Schnarch, 2004). This was achieved through having the project led by and carried out for Indigenous youth. The study was guided by the National Indigenous Youth Council on HIV/AIDS (NIYCHA, 2015) and adhered to their guidelines for research related to HIV, sexually transmitted and blood borne infections (STBBIs), sexual health, and harm reduction. Ethics approval was received from York University. In addition, we consulted with relevant leadership in each community prior to initiating data collection and (where necessary) modified our procedures to accommodate local requests.

The study adopted a community-based participatory research design, grounded in a decolonizing methodological orientation. Decolonizing methodologies insert Indigenous perspectives into Western research paradigms (Wilson, 2008). Decolonizing methodologies are about changing focus, “centering our [Indigenous] concerns and worldviews and coming to know and understand theory and research from our own perspectives and for our own purposes” (Smith, 1999, p. 39).

Although often “quantitative work is seen as both foreign and as the epitome of colonizer settler research methodology in action” (Walter & Andersen, 2013, p. 130), it may provide an avenue for reshaping social realities if such methods are framed by an Indigenous worldview. Historically, statistical outcomes of quantitative methods have produced narrow “lenses through which most people think about and ‘understand’ Indigenous peoples today” (Walter & Andersen, 2013, p. 14). Yet, through an Indigenous lens, quantitative methods have the potential to benefit Indigenous communities by informing policy that can support concrete, positive, and political change (Walter & Andersen, 2013; Wilson, 2008).

We employed a brief structured survey that was developed by Indigenous youth leaders, with support from NYSHN staff and a researcher at York University. It was piloted and refined with members of NIYCHA. The survey was administered electronically, on offline iPads to enhance ease of data capture and usability. As this was a pilot study to test the feasibility and acceptability of the SHC, sample size calculations were not done (Thabane et al., 2010).

A group of Indigenous youth leaders went on the powwow trail to four Ontario, Canada, powwows with the SHC during the summer and fall of 2014. Approximately four youth leaders attended each SHC to facilitate. Following informed consent, the survey was administered to Indigenous youth ages 16 to 25 who came to the SHC. Informed consent was achieved before youth started the survey by providing each participant with detailed project information (purpose of study, risks, benefits, etc.), including the contact information of the project leaders and ethics board. Youth leaders went through each detail with participants and answered any questions they had before giving them the iPad. Recruitment was done through asking youth who approached the SHC if they fit inclusion criteria of being within the age range 16 to 25, could speak/understand English, self-identified as Indigenous, and if they had engaged with the SHC games and booths for a minimum of 5 minutes. Where literacy or comprehension assistance was

² OCAP[®] is a registered trademark of the First Nations Information Governance Centre (FNIGC; www.fnigc.ca).

needed, one of the youth leaders would facilitate administration. Surveys were completed with youth who fit inclusion criteria and provided informed consent. Data collection occurred over an average of 2 to 3 days at each powwow, starting each day at approximately 10 a.m. and ending at 6 p.m. The 18-question survey took an average of 3 to 5 minutes to complete and queried within six major areas of interest: (a) experience of satisfaction and comfort with the SHC and willingness to return; (b) perceived suitability of doing HIV prevention outreach with youth at powwows; (c) intention to engage in any sexual practices and/or drug use at the powwow; (d) intention to use harm reduction supplies (e.g., condoms); (e) history of sexual practices and drug use; and (f) sociodemographic information. Youth who filled out the surveys were eligible to win an iPad mini through a draw at the end of each powwow.

Survey responses were exported to SPSS. Means, frequencies, and standard deviations for the following variables were examined: sociodemographic characteristics (e.g., gender, age, rural/urban, sexual orientation, Nation); satisfaction with the SHC; comfort level with the SHC; and willingness to return to the SHC.

Results

More than 300 youth engaged in SHC activities, and 154 eligible youth filled out the survey (Table 1). Half of the youth who engaged with the SHC did not complete the survey because (a) they were not eligible (e.g., under 16 years of age, over 25 years of age, or did not self-identify as Indigenous); or (b) they did not want to fill out the survey (a minority). Given the sometimes tumultuous nature of doing outreach at public events, it is understandable that some youth might not have wanted to take the time to participate.

Table 1

Demographics for Survey Participants, N = 154 (Ages 16–25, Mean = 19.6, SD = 3.5)

Survey question	Variable	Youth responses		Response rate (%)
		<i>n</i>	%	
Gender identity	Female	106	68.8	100.0
	Male	40	26.0	
	Other	8	5.2	
Sexual orientation	Heterosexual	118	76.6	94.2
	Other	27	17.6	
Indigenous identity	Indigenous	16	10.4	100.0
	Aboriginal	55	35.7	
	First Nations	75	48.7	
	Métis	7	4.5	
	Inuit	1	0.6	

Survey question	Variable	Youth responses		Response rate (%)
		<i>n</i>	%	
Where do you live?	On this reserve	70	45.5	100.0
	On another reserve	14	9.1	
	Off reserve in a city	47	30.5	
	Off reserve in a rural area	11	7.1	
	Off reserve in the suburbs	4	2.6	
	Other	8	5.2	

The vast majority of respondents identified as First Nations, and nearly half (46%) lived on the reserve that hosted the gatherings. A total of 4.5% of youth identified as Métis, and one person identified as Inuit. Sixty-nine percent identified as female, 26% as male, 3% as trans or gender nonconforming and 2.2% selected other. Three-quarters identified as straight or heterosexual, and 17.6% identified as lesbian, gay, bisexual, queer, questioning, or two-spirited, and 6% did not respond (Table 1).

Table 2 presents the behaviours and intentions of participants relevant to HIV prevention. Eighty-two percent of the sample reported having had sexual intercourse. In the last 12 months, 27% had two or more sexual partners. Forty-two percent had not used a condom the last time they had sex. In addition (not shown in Table 2), 15% of those who participated had injected a drug in their lifetime.

In terms of their perceptions of the context, 40% of youth thought that “a lot” of sex happens at powwows, 23% said “normal—same as at home,” 37% said less. Fourteen percent said they were either “definitely” or “probably” going to “hook up” or be sexual with someone at the powwow, an additional 14% were not sure. However, 62% of youth said that *if* they did “hook up” with someone at the carnival, they would use a condom that they received at the SHC. Nearly 50% of youth felt that “a lot” of drinking and drugs happened at powwows, while 21% believed it happened at “a normal amount”. Almost 20% thought that they would either “probably” or “definitely” get drunk or high with someone they met at the powwow; 15% were undecided.

Table 2
HIV Prevention Behaviours and Intentions of Survey Participants (N = 154)

Survey question	Variable	Youth responses		Response rate (%)
		<i>n</i>	%	
We understand that having sex or sexual intercourse means different things to different people. In your opinion, have you had sex?	Yes	126	81.8	98.7
	No	17	11.0	
	Not sure	9	5.8	

Survey question	Variable	Youth responses		Response rate (%)
		<i>n</i>	%	
How many people have you had sex with in the past 12 months?	0	30	19.6	99.4
	1	69	45.1	
	2	19	12.4	
	3	6	3.9	
	4 or more	17	11.1	
	Don't know	2	1.3	
	Prefer not to say	10	6.5	
The last time you had sex, did you or your partner use a condom?	I have never had sex	23	14.9	100.0
	Yes	67	43.5	
	No	64	41.6	
How much sex between young people do you think happens at powwows?	A lot	61	39.6	100.0
	Normal—Same as at home	36	23.4	
	A little bit	44	28.6	
	None	13	8.4	
How likely are you to hook up with someone at this powwow?	Definitely not	78	50.6	100.0
	Probably not	32	20.8	
	Not sure	22	14.3	
	Probably yes	16	10.4	
	Definitely yes	6	3.9	
If you “hook up” with someone, do you plan on using the condoms you got here at the Sexy Health Carnival booth?	Yes	95	61.7	100.0
	No	14	9.1	
	Not sure	11	7.1	
	I am not having sex	34	22.1	
How many youth do you think do drugs and/or drink alcohol at powwows?	A lot	73	47.4	100.0
	Normal—Same as at home	33	21.4	
	A little bit	34	22.1	
	None	14	9.1	
How likely are you to get drunk or use drugs (get high) with someone you met at this powwow?	Definitely no	79	51.3	100.0
	Probably no	23	14.9	
	Not sure	23	14.9	
	Probably yes	22	14.3	
	Definitely yes	7	4.5	

Table 3 shows youth reactions to the SHC. Overall, youth rated the SHC positively (80% rated it as “awesome”; another 20% thought it was “okay”). Ninety-nine percent said they would return to the SHC at future events. Despite the enthusiasm for the SHC, there was a range of responses in terms of how comfortable youth felt visiting the SHC in a powwow setting: 41% were very or somewhat uncomfortable, 14% were neutral, and 44% were comfortable or very

comfortable. However, when asked whether powwows were a good place to talk about sexual health and HIV, 96% agreed. Ninety-four percent felt that incorporating culture was somewhat or very important for sexual health education with Indigenous youth.

The survey also provided the opportunity for youth to offer open-ended comments. Topics that some youth wanted to learn more about in future iterations of the SHC included: sex addiction, healthy relationships sexually/emotionally/physically, midwifery, LGBTQ communities, and symptoms of drug and alcohol abuse. These topics were each requested only once.

Table 3
Responses to the Sexy Health Carnival (N = 154 Survey Participants)

Survey question	Variable	Youth responses		Response rate (%)
		n	%	
How would you rate the sexy health carnival?	It sucked	0	0	100.0
	It was okay	30	19.5	
	It was awesome	124	80.5	
Would you come back to the Sexy Health Carnival booths at future powwows?	Yes	153	99.4	100.0
	No	1	0.6	
How comfortable did you feel visiting the Sexy Health Carnival today?	Very uncomfortable	48	31.2	99.4
	Somewhat uncomfortable	15	9.8	
	I didn't think about it	22	14.3	
	Comfortable	26	16.9	
	Very comfortable	42	27.3	
Do you think powwows are a good place to talk about sexual health and HIV?	Yes	147	95.5	100.0
	No	7	4.5	
How important is culture for sexual health education of Indigenous youth?	Somewhat important	28	18.2	100.0
	Very important	117	76.0	
	Not sure	9	5.8	

In addition, we offered youth an opportunity to participate in our “speaker’s corner,” where they were encouraged to share their thoughts and feelings about the carnival by speaking into a digital recorder anonymously. Comments from 12 youth participants who offered their feedback were later transcribed and coded. Four key findings emerged:

- 1. Youth preferred the SHC to school-based sexual education.** Many youth noted that the carnival was “much more fun than sitting in a classroom.” One youth said, “This is useful ... because you’re getting educated while playing games.” Another noted that “I felt I learnt a lot more here than in school. In school they never taught us how to put on condoms. Sex ed only told us about STDs and how we can get them.”

2. **Youth appreciated the positive focus.** Several youth appreciated that the content didn't "shame" or stigmatize youth sexual health. Instead, it taught them "a lot about sexual things and what can and cannot happen," rather than just focusing on the negative. Furthermore, youth of varying sexual and gender orientations identified feeling safe at the SHC: "This is a lot better than sex ed class. I hate being pushed off to a different side in sex ed class because I'm gay. I almost failed sex ed class." Many youth described feeling welcome and accepted at the carnival and thought that it was an overall "cool place to hang out."
3. **Youth liked the free condoms.** They said condoms are very expensive, and many did not know where to go to get free condoms in their communities. A few youth appreciated the information on alternative forms of protection. For example, one youth said, "I am happy that you guys have this tent here because most girls don't use protection and that's why they get pregnant when they're young."
4. **Youth felt that the SHC is important to have at powwows.** For example, one youth noted, "I think it is really great that you have this here, it's really important. I've only been here for 2 minutes and instantly I was drawn to this tent because these are conversations that people don't have; and to spread this awareness for Indigenous people is really important." Youth shared feeling more informed and confident with regards to sexual health and HIV information after participating in SHC activities.

Discussion

This peer-led pilot project provides preliminary but compelling evidence that the SHC intervention is welcomed by Indigenous youth in powwow settings and is being received favourably by its target audience. Further, youth reported the intention of using condoms acquired at the SHC, suggesting that the SHC holds promise in increasing access to safer sex resources.

Based on these preliminary data, we note that we are reaching youth who may be vulnerable to HIV (based on their sexual and drug histories) with an intervention and resources about which they are enthusiastic. Youth respondents indicated that a lot of sex and drug use is taking place at powwows. However, many youth respondents also stated that they did not personally engage in either of these behaviours. Two plausible explanations for this discrepancy are (a) youth may overestimate the sexual and drug activities happening, and (b) due to shame and stigma, youth may be reluctant to admit that they are participating in these activities and are therefore underreporting personal involvement.

Youth who were sexually active indicated that, although their use of condoms was low with previous partner(s), they were very likely to use condoms provided by the SHC. This result may be due to social desirability bias, where youth respondents answer based on what they assume researchers want to hear (Mortel, 2008). However, it may also be due to the SHC making youth feel comfortable to take the free condoms, as the SHC was an informal and welcoming

atmosphere, with a large number of condoms that were readily available for youth. Youth facilitators encouraged visitors to take the free condoms, along with engaging in conversations around condom styles, flavours, and brands. The SHC was a culturally safe space that provided sexual health facts and resources in an accessible, nonjudgmental, and supportive manner.

Survey results revealed that “culture” is fundamental to sexual health education for Indigenous youth, and powwows are an important place to discuss sexual health and HIV. In our case, the SHC explicitly engaged culture by referencing traditional languages, teachings, and ceremony. It also implicitly embraced culture through the leadership of Indigenous youth peer educators. According to Devries, Free, Morison, & Saewyc (2009), incorporating culture into educational curriculums has been associated with increased condom use among young Indigenous men in Canada aged 12 to 20 years. Further, according to Wilson et al. (in press.), the incorporation of culture, community, history, and tradition in sexual health education is essential for effective HIV prevention and health promotion initiatives for Indigenous youth.

The majority of youth respondents indicated that they would come back to the SHC at future powwows. Despite this, a large number of youth also said that attending the SHC made them feel uncomfortable. Gilley (2006) similarly states that it is “widely acknowledged that Native peoples, especially people who are now in their late-20s and older, are uncomfortable discussing or acknowledging sexuality in public forums” (p. 560). Youth may be uncomfortable because of ingrained notions of stigma or shame around sexuality, particularly sexually transmitted infections (Restoule, Campbell McGee, Flicker, Larkin, & Smillie-Adjarkwa, 2010; Worthington et al., 2010). For example, Flicker, Larkin, et al. (2008) conducted six focus groups with 61 Indigenous youth and found that some communities isolated individuals when it was discovered that they were diagnosed with HIV. This is mainly due to ongoing colonial legacies of residential schools as noted above (Flicker, Larkin, et al., 2008; Negin, Aspin, Gadsden, & Reading, 2015).

More young women attended the SHC and filled out our survey than young men. Lower rates of male participation in sexual health promotion activities are not uncommon, and may be due to dominant constructions of gender that position sexual and reproductive health as “women’s issues” (Flicker, 2009). Lower male participation may have been exacerbated by the SHC having predominantly female youth facilitators. More effort must be made to find strategies that reach young Indigenous men with HIV prevention and sexual health education.

In response to discomfort, Gilley (2006) found that a sexual health outreach method called “Snag Bags” acted as a cultural mediator between discomfort/shame, and reaching Indigenous youth prior to engaging in sexual behaviours. The Snag Bags are brown paper bags that contain STI and HIV prevention resources and local healthcare information; these bags are distributed at powwows and/or 49ers. Disguising the condoms and sexual health resources made distributing them through social spaces more efficient, while making youth feel comfortable about receiving sexual health resources in a public space (Gilley, 2006). Similarly, the SHC provided youth with brown paper “loot” bags to fill with free condoms and sexual health resources. Although some youth indicated discomfort with the SHC, the bags may have proven

effective, as evidenced by a majority of sexually active youth indicating that they were likely to use condoms provided by the SHC.

Finally, although an estimated 300 youth were reached overall, a significant barrier to participation may have affected the number of youth who filled out the iPad survey. One powwow that the SHC visited was moved from outdoors to inside a roundhouse due to storm conditions. While the weather conditions were assumed to play a role in the low attendance, some community members expressed their discomfort with the idea of having the SHC moved into a sacred place. The community members' concerns may also have potentially impacted participation, as some youth did not want to disrespect adults in the community by participating. A NYSHN youth facilitator (who was also a member of the community) spoke with community members and explained that the SHC provides information to try to keep individuals, the land, and communities safe. The youth facilitator indicated that "there is nothing more sacred and in the footsteps of our ancestors than revitalizing the ways of learning and teaching each other," by action (the actual existence of the SHC and the interactive experiences) and orally (conversations that are sparked from the booths/games). Ultimately, the Chief of the community intervened, expressing that the SHC's presence in the roundhouse was important, powerful, and should happen, given that the roundhouse is a place for safety. This experience underscored the importance of building community support and liaising with local leadership in order to garner support for this work.

Limitations

Although youth respondents were from different communities, Nations, and contexts, the survey sample was not representative of all Indigenous youth in Ontario or Canada. Moreover, due to small numbers of eligible youth, the survey respondents' answers were grouped together, resulting in a pan-Indigenous summary of the results. Furthermore, the sample was not random, representing only youth who engaged with the SHC in specific powwow settings. Nevertheless, this project contributes to the limited literature unpacking how to promote sexual health for Indigenous youth in a culturally safe powwow context.

A second limitation stems from the lack of privacy that youth respondents had while filling out the iPad survey. Powwows have very social, busy, and fast-paced atmospheres. Youth who attend powwows typically come and walk around with friends and/or family members. Given the informal atmosphere of the SHC and the survey, youth who filled out the iPad survey may not have accurately responded to the questions for fear of others looking at their answers.

A third limitation relates to the busy and social atmosphere of powwows, where friends and/or family want to keep mobile and may not want to stay in one location for very long. Although youth leaders took this into account when developing the survey, youth survey respondents may have felt pressured to get through the survey quickly, thus perhaps undermining accuracy.

A fourth limitation is the brevity of the survey. Youth who led development of this survey strongly advocated for its short length. This resulted in a small number of survey items

and a lack of formal measures. As such, it was difficult to do robust analyses, and instead we relied on frequencies tabulated for this report. Future research could include scales with established reliability and validity to assess constructs such as cultural connectedness, HIV knowledge, and safer sex self-efficacy. Conducting a pre- and post-test survey design in future research would also provide an opportunity to evaluate the impact of the SHC on participants' safer sex practices, safer sex self-efficacy, and HIV knowledge.

A fifth limitation is the small number of youth who participated in the speaker's corner. It seemed that only those most enthusiastic about the intervention took the extra time to share their thoughts. As a result, care should be taken in interpreting the qualitative results.

Despite these limitations, the iPad surveys were deemed fun, easy, and accessible. The iPads generated enthusiasm, given youth knew that they had a chance of winning one at the end of the powwow. The iPad software also allowed for multiple iPads to be used offline for data collection, with the results collated in one database at a later time. Data collection and entry were expedited by this process, greatly reducing the time and resources needed for data entry after the powwows.

Conclusion

When given the opportunity, support, and appropriate setting, Indigenous youth can develop successful sexual health outreach and HIV prevention resources that are attractive to their peers. The National Aboriginal Youth Strategy on HIV and AIDS (2010) recommends “real and meaningful Aboriginal youth participation and engagement that provides supportive spaces for Aboriginal youth to share, create strong partnerships, build capacity and skills, and be empowered to influence policy, programming and education about HIV and AIDS” (p. 5).

This pilot implementation project was by and for Indigenous youth. Gilley (2006) notes, “Instead of simply ‘translating’ HIV/AIDS programming into Native culture, HIV prevention strategies must be de-colonized and integrated by Native peoples into their own disease theories and contemporary culture” (p. 561). Too often, healthcare providers make the mistake of imposing an agenda on Indigenous communities that providers have developed in isolation of the communities themselves (Koster, Baccar, & Lemelin, 2012). Young people's skills and talents are regularly underestimated by both the mainstream public and the academic research community (Checkoway & Richards-Schuster, 2004). This project illustrates that Indigenous youth are capable of reaching their peers and developing successful sexual health outreach and HIV prevention resources for each other.

The results from the iPad survey suggest that culture is very important in sexual health education. Although the Canadian Constitution recognizes Indigenous Peoples as First Nations, Métis, and Inuit, these are administrative distinctions that relate to the Canadian government's attempts to govern the diversity of Indigenous Peoples in Canada (Indigenous and Northern Affairs Canada, 2012). Indigenous communities are much more diverse with respect to cultures, traditions, and languages than recognized by the Constitution. The SHC was developed by an

Anishnaabe youth and her community, and brought to four First Nations communities. This may have resulted in the survey responses being mainly from First Nations youth. In order to reach out to the diversity of Indigenous youth across Turtle Island, the SHC, along with future sexual health outreach and HIV prevention methods, must not take a pan-Indigenous approach, and instead must be catered to unique and local community contexts.

Based on comments provided by the youth participants, there is a need to provide further information on topics such as sex addiction, healthy relationships (sexually, emotionally, and physically), midwifery, LGBTQ communities, and symptoms of substance use. Given the lack of privacy at the SHC to fill out surveys, many youth may have been reluctant to provide honest comments, hence the above topics being requested only once. Thus, it is important to note that the few youth who did provide comments on the SHC may have views representative of the needs in their communities, and their comments should be taken into consideration for future SHCs.

Finally, more work needs to be done to reduce stigma around STIs and increase comfort levels. Stigma and shame are the real “risks” for individuals and communities impacted by HIV (T. Annett, personal communication, August 29, 2014; Lesperance, Allan, Monchalin, & Williams, 2015; NIYCHA, 2015). Flicker, Larkin, et al. (2008) note that “education; teaching of traditional values around sex, disease, and homosexuality; and finding a role for people living with HIV in prevention work may help reduce the discrimination against people with HIV and ultimately be a prevention strategy” (p. 192). Further, HIV prevention programming that involves the reclamation of history and culture may work to challenge stigma attached to HIV and AIDS (Lakhani, Oliver, Yee, Jackson, & Flicker, 2010). This pilot implementation project is a step forward in reducing stigma in a community setting by adopting a peer-led, culturally safe approach. It is a prime example of how future sexual health outreach needs to shift attention away from barriers and shaming, and focus on strengths and empowering Indigenous youth (NIYCHA, 2015).

Our team was recently funded to continue this work by adapting the SHC and taking it to nine more Indigenous gatherings (three First Nations, three Métis, three Inuit). Future research will explore adapting the SHC to unique community settings and incorporating HIV prevention in diverse contexts. We look forward to continuing to share results.

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Positive Leadership, Legacy, Lifestyles, Attitudes, and Activities for Aboriginal Youth: A Wise Practices Approach for Positive Aboriginal Youth Futures

Abstract

Adolescence is a dynamic and complex period in any society, but within the Aboriginal population this time is one of significant social pressures, critical decisions, and struggles to emerge healthy. The Positive Leadership, Legacy, Lifestyles, Attitudes, and Activities for Aboriginal Youth (PL³A³Y) project created youth and Elder teams to explore cultural practices that may inform the youth's paths to living well. Using a community-based participatory research approach, Elder–youth dyads developed and delivered five modules to 78 students at a local elementary school in response to the research question: What are the critical components of a “Living Well” healing initiative for Aboriginal youth? Through a 4-step process that included engagement, module creation, co-delivery, and knowledge sharing, the project's community-based research team innovatively and using culturally appropriate approaches brought forward critical topics of Leaders and Leadership, Legacy, Lifestyles, Attitudes, and Activities. Not only did the Elder–youth dyads develop a series of highly relevant, creative, useful products that were shared extensively with youth in the community, but the experience became a culturally appropriate leadership development opportunity for the youth researchers. The involvement of Elder–youth teams was a strength in linking past to present and in jointly envisioning a positive, healthier future for Aboriginal youth. With youth as co-researchers, the Elders as partners were highly effective in the development and delivery of culturally relevant teachings and knowledge that strengthened youth's ability to achieve holistic personal and community wellness.

Keywords

Aboriginal, youth, Standing Buffalo First Nation, Dakota community-based research, adolescents, Elders

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Introduction

Health inequalities and negative health trends persist in Canada's Aboriginal population. This reality is most pressing for Aboriginal youth, who are already known to be at risk for lower life expectancies (Tjepkema, Wilkins, Sénécal, Guimond & Penney, 2010), increased illness rates (Garner, Carrière, Sanmartin, and the Longitudinal Health and Administrative Data Team, 2010), growing mental health needs (Health Canada, 2015), and high incarceration rates (Assembly of First Nations, 2011) when compared with their non-Aboriginal counterparts.

Traditionally, adolescence is positioned as the south of the four directions and represents the summer: the time to learn, explore, and uncover life roles and skills (Douglas, 2013). Colonialism altered the Indigenous context for youth socialization (Preston, 2002), displacing youth from traditional decision-making processes (Hylton, 1999) and creating disillusionment and disengagement of youth from their communities, an effect that persists. The healthy and holistic development of Aboriginal youth is contingent upon engaging them back into their culture and traditions to better understand themselves and their place in society.

Rationale

Demographics. While statistics on the health status of Aboriginal populations are discouraging, more information about factors affecting health is needed to facilitate appropriate planning and policy decisions (Critchley et al., 2006). The Aboriginal population is young, with a median age of 26 as compared to 40 for the non-Aboriginal population, and approximately 48% under the age of 24 as compared to 31% in non-Aboriginals (Statistics Canada, 2011). As of 2011, Aboriginal children (14 and under) make up 28% of the Aboriginal population compared to 16.5% in the non-Aboriginal population. For the age group 15 to 24, Aboriginal youth make up 18.2% of the Aboriginal population compared to 12.9% representation of this age group in the non-Aboriginal population (Statistics Canada, 2011). Given this youthful demographic, a focus on the health and well-being of Aboriginal youth as a subgroup is merited.

Aboriginal knowledge and wellness. Canadian Aboriginal people speak of traditional healing as including activities that range from traditional medicines to promotion of psychological and spiritual well-being, to using traditional ceremony, songs, counselling, and the accumulated wisdom of Elders (Royal Commission on Aboriginal Peoples, 1996). Recognizing the validity and importance of traditional medicine and practices and including them within health services is critical to improving the health status of Aboriginal people (Clark et al., 2013; Health Council of Canada, 2012; Martin-Hill, 2009). Traditional health practices and Indigenous knowledge are seen as protective factors for at-risk Aboriginal populations (Health Council of Canada, 2012; Martin-Hill, 2009) as well as essential pathways to community wellness (Bennett, 2015; Martin-Hill & Soucy, 2005). Evaluation of community wellness must be based on an Indigenous knowledge framework (Stewart, 2007) in order to re-establish traditional collective forms of prevention and intervention strategies (Bennett, 2015; Crooks, Chiodo, Thomas, & Hughes, 2010; Health Council of Canada, 2012; Martin-Hill, 2009; Petrsek MacDonald et al., 2015).

Sustainable approaches. Researchers emphasize strategies for practice (storytelling, Elder involvement) and community capacity building (leadership building, cultural inclusiveness, mentorship) for Aboriginal health and healing (Crooks et al., 2010; Martin-Hill, 2009; Stewart, 2007). It is broadly recognized that holistic approaches are effective for improving and sustaining cultural, social, and personal prospects of Aboriginal youth. Children who enjoy healthy and active lives are less likely to exhibit self-destructive behaviours and are more likely to develop self-confidence and self-esteem (Petrsek MacDonald et al., 2015). Self-reported perceptions of health by Aboriginal youth (aged 13 to 18) indicate that 43% are healthy, 14% are somewhat healthy, 36% are unhealthy, and 7% are unsure (Lavallée, 2008). More importantly, these findings reflect a significant negative shift from previous self-reported health reports of Aboriginal children (ages 9 to 12) of 93% healthy and only 7% unhealthy (Lavallée, 2008).

Adolescent engagement and empowerment. Adolescence is the most intense period of identity development from personal, social, and cultural perspectives. At the personal level, youth struggle internally with building self-understanding, self-esteem, skills, and strengths, whereas at the social level, external pressures are towards relationship building, social role capacities, and social competencies (Stets & Burke, 2000). The Canadian Institute for Health Information (2004) indicated that strategies to improve the health of Aboriginal youth must consider the broad historical and social context, including reflection on power and governance issues, service provision challenges, and variable application of treaty rights. Kirmayer, Brass, and Tait (2000) assert that attempts at forced assimilation and cultural genocide of Indigenous people left many with “profound problems of identity and self-esteem” (p. 607).

Lalonde (2005) suggested that solutions for improving well-being of Aboriginal youth lie with the communities through lateral knowledge-exchange efforts and cross-community sharing of Indigenous knowledge. Aboriginal youth want healthy and meaningful lives, and they need to be engaged in developing the solutions that will heal and lead to sustainable health for them and their communities. “Healing youth today will lead to their empowerment tomorrow” (Royal Commission on Aboriginal Peoples, 1996, p. 181). Providing a forum for their voices to be heard and valued will support their empowerment and potentiate generational health (Crooks et al., 2010; de Finney, Green, & Brown, 2009; Martin-Hill, 2009).

Most research about Aboriginal youth has focused on biomedical issues, such as disease incidence, violence, and substance abuse. Our interest was in exploring historical, societal, cultural, interpersonal, and environmental influences on this youth. Through such an appreciative and holistic approach, we believed that Aboriginal youth would not only benefit in terms of health and wellness, but would be engaged in designing and implementing meaningful and sustainable programs in their communities.

Purpose

To better prepare youth for a positive future for themselves, their families, and their communities, **PL³A³Y** advocated, emulated, and developed “**Positive Leadership, Legacy, Lifestyles, Attitudes, and Activities for Aboriginal Youth: A Wise Practices Approach for Positive Aboriginal Youth Futures.**” The project was based at Standing Buffalo First Nation, a rural reserve located approximately 8 km northwest of Fort Qu’Appelle, Saskatchewan, Canada, with a total population of about 1,100 members and approximately 400 people resident on the reserve. Of note, 35.3% of the on-reserve population is currently 19 years of age and under (eHealth Saskatchewan, 2015). This project evolved over 8 years as the Okanku Duta Amani—Paths to Living Well program of research.

Aboriginal youth involved as research team members ranged in age from 16 to 19 and included both male (2) and female (4) participants. The emphasis of **PL³A³Y** was that these youth were not treated as passive objects for intervention (Farmer, 2008) but were actively engaged as capable and essential partners, especially in the pairings and interactions with Elders.

Sanders and Munford (2005) and more recently, Jardine and James (2012) suggested that inclusiveness and “real participation” of this subpopulation in research, policy, and practice is imperative to making a difference. This research was further situated within wise practices, as described by UNESCO (2002) and which Thoms (2007) described as reflecting the cultural heterogeneity, social diversity, and communal traditions of Aboriginal contexts while remaining dynamic and sustainable over time. Within this project, we understood “wise” practices to be those which are inclusive, locally relevant, sustainable, respectful, flexible, pragmatic, and encompassing of all worldviews, and which consider historical, societal, cultural, and environmental factors. **PL³A³Y** recognized variation and diversity in beliefs and traditions within an Aboriginal community and situated the effort within our understood wise practices (rather than best practices) approach.

This study aimed to answer the core question: What are the critical components of a “Living Well” healing initiative for Aboriginal youth? Sub-questions included: (a) What do Aboriginal youth consider positive and healthy choices? (b) How do Aboriginal youth see the connection between “Living Well” and personal and community health?

Methods

Understanding what constitutes wellness (i.e., Okanku Duta Amani [Dakota]; Miyo-Mahcihoyan [Nehiyawak—Plains Cree]) from the perspectives of Aboriginal Peoples remains foundational to achieving holistic wellness. The meaning of health varies, is challenged, and becomes derailed within the complexities of the individual and collective experiences and realities facing Aboriginal youth today.

The original research funded by the Canadian Institutes of Health Research informed this 1-year **PL³A³Y** initiative to operationalize positive choices voiced by youth. The project used the template of Leadership, Legacy, Lifestyles, Attitudes, and Activities within Standing Buffalo First Nation. The methodology used for **PL³A³Y** was a community-based participatory research (CBPR) approach (Macaulay et al., 1999; Minkler & Wallerstein, 2008). At its essence, CBPR seeks new approaches to community-specific challenges through collaboration, participation, empowerment, and transformative change (Hills & Mullet, 2000; Moffitt & Robinson-Vollman, 2004). CBPR highlights the centrality of the community in operationalizing its research agenda for preferred futures with respect to control (Schnarch, 2004), self-determination (Schnarch, 2004), ethical frameworks (LaVeaux & Christopher, 2009), and equitable involvement (Government of Canada, 2016). This method employs a collaborative approach to investigation that engages participants as equals in all phases of the research process. Such a model is focused on knowledge gathering as well as action to address pressing community issues. The assumption is that people are knowledgeable about their environments and are capable of developing more awareness by becoming full participants in the research process. It was imperative to recognize and address challenges related to working with youth as co-researchers.

Methodologies such as CBPR represent a launch pad for the recognition and inclusion of Indigenous epistemologies and community participation (Sinclair, 2003). Stewart (2007) stated that “Indigenous health research should reflect the needs and benefits of the participants and their communities as well as academic and practitioner interests ... while reflecting Indigenous values and philosophies” (p. 57).

This project was conceptualized as having four phases: 1) engagement (partnering and team building), 2) co-creation activities, 3) co-delivery (data collection and analysis), and 4) knowledge sharing. Through a CBPR approach it was possible to bring various perspectives and stakeholders together in an active and inclusive manner. Further, this approach allowed the community members to not only participate in but also lead and own the process and products. Finally, CBPR was seen as a preferred approach to creating and facilitating an environment in which the youth researchers and the Elders could strengthen and support each other in increasing community wellness.

Phase 1: Engagement—Community Partnering and Team Building

This phase built upon the existing partnership with many of the proposal team members and the Standing Buffalo First Nation community. It included securing the participation of three community Elders, a community Research Coordinator, and a student research team (comprising six youth between 16 and 19 years of age). The Elders (both male and female) involved with this project had long-term involvements with the researchers and volunteered to continue their efforts to improve the well-being of the youth. Under the leadership of Elders, the project was launched with a community feast, which included academic members. Following community endorsement, the research team assembled for an orientation day to introduce the project, confirm research parameters (i.e., timelines, team building, ethics), and clarify roles. Of special note, the six youth researchers were given choices with respect to involvement (or non-involvement) in any aspect of the research. A main outcome of the orientation was to establish the agenda and Elder–youth dyads for a day long “Culture Camp” to be held at the local school.

Phase 2: Co-development of PL³A³Y Modules

This phase enabled the research team to develop a series of five **PL³A³Y** modules to be delivered during the Culture Camp. The method was a *learning circle* rooted in Aboriginal ways of learning and precipitating social change (Baldwin, 1998) and used an assets/strengths based approach. Two or more learning circle cycles were undertaken for each module to encourage open dialogue, team building, and creativity around the development of modules reflecting each critical aspect of **PL³A³Y**, described herein. Elder–youth dyads or triads (with academic observers) naturally coalesced around the individual modules based on personal interests (Petrucka, Bassendowski, Bickford, & Goodfeather, 2012). Each module was developed independently, with wise practices delineated and articulated for each. This development was rooted in the awareness that incorporating knowledge of Indigenous history and culture is important in strengthening the relationship between mentor and mentee (Klinck et al., 2006).

Module 1: Leaders and Leadership. Aboriginal leadership models are often defined in terms of skills, abilities, and traditional gifts underlying an individual's traditional-spiritual name, clan, life experience, or Aboriginal identity (Cowan, 2008; Warner & Grint, 2006). Aboriginal leadership development is based on mentoring from the community's traditional teachers, healers, and Elders. Yet, Aboriginal youth are equally effective role models, accountable to their communities and bearing their own leadership responsibilities to support and develop leadership characteristics in others (King, 2008, para. 4).

The **PL³A³Y** Leadership Module reflected many works (Nuu-chah-nulth Tribal Council, 2007; Ottmann, 2005) recognizing that Aboriginal leadership development begins early in life, necessitating active nurturing and constructive direction. Youth who are engaged in positive activities and who feel accountable to their communities are more likely to participate in healthier behaviours, develop self-esteem, and experience improved mental health (Odawa Native Friendship Centre, 2013). In this project, evidence of youth's leadership growth emerged with increased involvement, assumption of roles and commitment, as well as with sharing learnings/ experiences within their community and beyond (Petrucka et al., 2012).

Module 2: Legacy. The challenge is to enable future generations to embrace traditional roles and understand how history relates to who they are (AFN Youth Council, 2007). Knowledge of an Aboriginal language is a positive predictor of increased self-esteem in youth and community wellness (Abraham, 2010), yet the trend is for fewer Aboriginal youth to use their mother tongue, and mother tongue continuity is declining due to departure from community of origin (Norris, 2003).

Within the discourse on Aboriginal knowledge, Castellano (2008) notes that there is emphasis on its timelessness. At times, knowledge is received as a gift; at other times, it manifests as "the time is right" to make a decisive turn in one's life. There is a recognized need to return to ancestral "wise practices" and engage community members, from youth to elders, in a reassertion of traditional beliefs, values, and ceremonial practices (Cowan, 2008). The Legacy Module considered the powerful role that culture plays in forming the identity of Aboriginal youth. History, language, and traditions were highlighted as critical elements informing positive choices.

Module 3: Lifestyle. Youth need more information, access to appropriate services, improved skills, and opportunities to seek healthy lifestyles in order to lead productive and fulfilling lives. Aboriginal youth manifest unhealthy lifestyle choices, such as poor diets, smoking, and drinking, disproportionate to their non-Aboriginal counterparts (First Nations Information Governance Committee, 2005). However, there is evidence that increased access to traditional healers and Elders is essential in the pursuit of balance (Williams, Guenther, & Arnott, 2011). The Lifestyle Module focused on awareness, issue deconstruction, strategies, and supports for youth in making sound complex decisions.

Module 4: Attitudes. Attitude towards self is dominant during adolescence. Having a good attitude towards oneself is the foundation of healthy self-esteem. Youth must have the confidence to perform and transition effectively, founded on a positive self-image. The Elder–youth dyad facilitated an activity in which positive attitudes were depicted on ceiling tiles for display in the school. The Elders based the activity on traditional storytelling, and the youth researchers spoke about positive attitudes and choices. Each participant was encouraged to select an aspect of health or self-care and visually display their theme for others to see and reflect upon. The Attitudes Module focused on exercising the personal within the social context. Youth often see themselves as disempowered in the context of the community, so this module reframed them as holding power and voice.

Module 5: Activities. A game is defined as a “pleasurable expression of voluntary participation in organized play, in which there are agreed-upon procedures and uncertain outcomes” (Cheska, 1979, p. 227). Traditionally, games played an important part in a holistic life for Aboriginal people (Turner, 2003), by establishing gender roles and responsibilities, fostering group identity, enhancing decision making, teaching youth about traditional spiritual beliefs, and imitating adult life (Palmer, 2003). Some games were purposeful in improving dexterity (e.g., bow and arrow), physical skills (e.g., horsemanship), or mental acuity (e.g., math skills). The Activities Module emphasized that physical activity not only contributes to health but can also create spaces for Aboriginal youth to exercise agency as well as produce cultural representations (Robidoux, 2006), which were enhanced through the use of traditional activities.

Phase 3: Co-Delivery of School-Based Culture Camp

Module delivery, along with related data collection, was launched during an evening event followed by a full-day Culture Camp at the Standing Buffalo Elementary School with senior students (aged 11 through 13). Participants were divided by gender (as appropriate to the Activities Module events) the evening prior to the full camp. During this 2-to-3-hour pre-Culture Camp event, the school participants were given information about the cultural game or activity according to gender and cultural norm. Following the activity, school participants provided a one-to-three-sentence vignette on what they learned and what was relevant in terms of cultural and/or historical relevance. The following day a rotating schedule through the remaining four modules was executed in various locations throughout the school. School participants took part in two morning sessions, a traditional lunch, and two afternoon sessions.

Module 1: Leadership. The Leadership Module included reflection and storytelling about leadership, including a recounting of historical and current leader vignettes by a Elder–youth dyad. Storytelling to explore leadership is a highly appropriate method to gain an appreciative understanding (Bushe, 2005). Youth researchers/leaders consistently learned and

role-modeled leadership under the mentorship of the Elder. Presentations were audio/video recorded. The proposed analysis has yet to be completed by the Elder-youth dyad.

Module 2: Legacy. The Legacy Module offered examples of local traditions (pictures, stories) using language as the focus. The topics included the role and meaning of dance, how to treat an eagle feather, and traditional activities such as the feast and powwow. A number of stories were captured in audio format.

Module 3: Lifestyle. In the Lifestyle Module, the Elder-youth dyad creatively used mirrors in revealing the seven mysteries of self in the Dakota traditions. According to the Elder, “the gifts of the Creator need to be reflected in each of us in our everyday lives, and the mirror becomes the way for us to capture and reflect this” (Elder CW, personal communication, February 10, 2012). Participants were invited to identify common lifestyle choices and positive role models/networks available to help them with these choices.

Module 4: Attitudes. In depicting an individual’s likelihood of being or becoming well, participants reflected on how they acquire and build positive attitudes. The Attitudes Module emphasized self-esteem and confidence building, with participants converting their reflections to pictures on ceiling tiles to reflect and share these attitudes.

Module 5: Activities. The Activities Module encompassed traditional gaming as a way to promote physical and social activities, as well as holistic health through purposeful games. During **PL³A³Y**, male youth participated in the Moccasin Game, with their female counterparts making feast skirts.

Phase 4: Knowledge Sharing

Although the final phase numerically, knowledge sharing was woven throughout the project. All modules were printed and distributed to Culture Camp participants and other interested parties. Discussions occurred with the local school about placing “created” resources in their libraries and public access areas. Youth interacted with Elders and academics to exchange ideas, plan innovations, and discuss the way forward. There was continual linkage with teachers and community leaders through the community researcher regarding the research intents.

Relationship

Researchers must “be aware that discussion of Indigenous knowledge is practical, personal, and contextual, and needs to be respected as such” (Pidgeon & Hardy Cox, 2002, p. 99). The research team involving Standing Buffalo First Nation and the University of Saskatchewan was built over eight years under the Okanku Duta Amani—Paths to Living Well research program focusing on youth wellness. The team consisted of Elders, community

researchers, and academic researchers, and it maintained an open linkage with the Standing Buffalo First Nation Chief and Council. Reflections on ethical principles were provided in a previous article (Petrucka et al., 2012) and the research methods adhered to the Tri-Council Policy Statement (CIHR, NSERC, & SSHRC, 2014). The research was approved by the University of Saskatchewan Behavioural Research Ethics Board – #12-192.

Limitations

PL³A³Y was a cross-sectional exploration of research led and implemented by youth and Elders in Standing Buffalo First Nation only. We recognize and respect distinctiveness of Aboriginal cultures and envision tailored replications in future sites. We understand that our pre-existing relationship with Standing Buffalo First Nation reduced the need for investment in youth development, leadership involvement, and community engagement, but that this may not be true in all settings. We recognize that not all Aboriginal community members are committed to traditional practices; hence, efforts must be made to respect and honour their decisions. Finally, we note that although there was a great deal of energy and interest in determining the content and delivery of the modules, there was limited interest in the analysis phases, although multiple efforts were made to engage the community teams.

Discussion

Reflection on Research Method

Stewart (2009) stated, “Indigenous health research should reflect the needs and benefits of the participants and their communities as well as academic and practitioner interests” (p. 57). CBPR potentiates acknowledgement and engagement across these groups (Sinclair, 2003), and it facilitates sharing power with the community (Abolson & Willett, 2004). CBPR is collaborative, participatory, empowering, systematic, and transformative (Hills & Mullet, 2000) - aligning with an Indigenous research approach. This is an innovative and acceptable research methodology as it values the knowledge of the study group while co-creating new knowledge that advances positive community engagement and development.

PL³A³Y used CBPR in seeking collaboration between youth, community, and academic researchers for the purpose of creating new knowledge and understanding about Aboriginal youth wellness. Collaboration engaged youth as consulted, informed participants and as partners (i.e., initiators and shared decision makers) (Hudson & Taylor-Henley, 2001), which necessitated efforts to ensure youth felt supported and gained voice; to confirm their abilities; and to provide time for task completion (O’Kane, 2000).

Role of youth. This project contributes to recognition of youth, generally, and on-reserve First Nation youth, specifically, as partners in health research. The method selected enabled participants to increase their personal and social identity and health as well as contribute to the identity and health of their community. Youth involvement contributed to their voices being

heard by their community and decision makers, which may influence these sectors in their understanding of and response to the needs of youth. In terms of building and sustaining the Elder–youth dyads, it was noted that there was a variable “lead,” with the role often alternating between the youth and the Elder. Without full investigation, but based on our observations, there was a sense that this dyad structure quickly mirrored a mentor–mentee relationship in many ways. The youth’s contribution to development and testing of the **PL³A³Y** modules will facilitate replication and modification for other Aboriginal communities.

Research capacity development. Through **PL³A³Y**, youth engaged in module development, but only minimally in other research components. Future capacity strengthening and encouragement are necessary to expose youth to all aspects of research as well as potential roles as co-researchers and community research navigators. Youth could have been more directly involved in developing consent forms and ethics approvals. This level of involvement might have helped keep the youth engaged when it came to analysis of the findings.

Reflection on Learnings

The following reflects learnings and potential future directions for the first three project phases.

Phase 1: Engagement. This phase built upon existing partnerships and strengthened emerging partnerships among the youth, Elders, communities, and academic research team. A research understanding was developed with three Elders, six youth researchers, and one community researcher with respect to the research protocols, ethics, funding allocations, and research sharing. Initially, this phase required academic involvement, but very quickly it became a community-driven component to which the academic representative(s) were invited. This approach respected culturally informed deep listening such that “the voices from the land, the spirit, and the people can be heard” (Sheehan & Walker, 2001)—voices not necessarily acknowledged within the Western research paradigm.

Phase 2: Co-development. Aboriginal youth are future stewards of their communities and cultures (Norris, 2008). This project embraced the Aboriginal pedagogical principle that knowledge is earned and must be demonstrated, so that the youth’s efforts to create and share for the good of their community are empowering (Castellano, 2008). Through **PL³A³Y**, engagement became empowerment as youth quickly adopted leadership roles with confidence and a sense of cultural identity in co-development and co-delivery of the modules. Overall, youth researchers indicated that their experiences were rewarding and especially valuable in relating with Elders. There were clear examples of how the youth self-selected to work with particular Elders as well as the extent to which they interacted with the Elders, which exceeded expectations and requirements. Further, we observed that the Elder–youth dyads lacked a single leader but rather there was evidence of shared leadership and enabled leadership (on the part of the Elders).

Phase 3: Co-delivery. The Culture Camp brought 78 student participants together for the full day, and of these, 26 were also involved in the pre-event (evening before).

Module 1. Participants heard stories from the Elder–youth dyad about historical and current Standing Buffalo First Nation leaders and discussed what it means to be a leader within Dakota traditions. Future Module 1 development may include participants providing a short audio clip regarding their understandings of leadership as well as provision of copies of stories to be accessible digitally for the school’s library.

Module 2. Participants were divided by gender due to Dakota cultural norms. The Elder led each group through a storytelling opportunity using local language building. Dakota language teaching is provided within the school, so many students have basic skills; however, the lack of access to resources (books, recordings) deters from the “living” legacy aspects. Efforts were made to capture stories in Dakota language “to be sure they are there for the future generations, as we are responsible [for preservation]” (Elder Velma Goodfeather, personal communication, February 9, 2012).

Participant descriptions were conceptualized under three themes:

Theme 1—Our Identity. Participants reflected how Dakota language provided them a unique identity.

It was good to hear the Elder tell us about our language and why it made us Dakota. (Participant ♂ B.)

Hearing the words spoken by Elder was different than learning in school. I felt special and that Dakota People were special because it belongs to us. (Participant ♀ S.)

Theme 2—Our Culture. Participants spoke of linking language to their understanding of Dakota culture.

The words are part of our history, and part of who we are and what we believe. The Elder told us how important it is to keep the language as part of culture. (Participant ♀ T.)

Theme 3—Our Community. Participants talked about how few people spoke or understood Dakota language, and how this was something the community needed.

Without language we will not be the same ... it would be sad. (Participant ♀ T.)

In the future, a cultural orienteering activity with an Elder was suggested, including creation of a cultural legacy map with photographs/sketches and markers to local cultural sites.

Module 3. Prior to the session, the youth and Elder identified priorities for lifestyle and agreed to use seven mysteries of self. The Elder used seven mirrors named with each mystery, which she used to facilitate a discussion of each mystery by asking participants how these played a part in how healthy they were or could be. Use of the mirror as a metaphor for self-reflection and humility is consistent with an Indigenous way of knowing. Four response dyads resulted from thematic analysis of responses. The youth leader in this module also spoke of how he interpreted each of the mysteries. This reflected an acknowledgement of multiple ways of knowing/understanding one's self.

Dyad 1: Self/Others. Participants spoke about choices made based on either one's own values or those of others, including peers and family.

Every day, every choice, it's about other people telling me what is right or wrong.
(Participant ♂ D.)

I try to listen to my parents and grandparents—I know they only want what is good. But when I am with my friends I want to be like them. (Participant ♀ R.)

Dyad 2: Winners/Losers. Participants voiced perceptions about whether one is a winner or a loser. This assessment included labelling of peers using drugs or even smoking as “losers.”

Dyad 3: Ancestral Culture/Modern Culture. Participants stated that those participating in cultural activities had healthier lifestyle behaviours than those who “clashed with” or “ignored” Dakota culture.

When we dance powwow we are at our healthiest ... our choices are good and make us healthy. (Participant ♂ F.)

If they don't do cultural stuff, they don't understand ... not well, using drugs and alcohol ... it is sad. (Participant ♀ S.)

Dyad 4: Easy/Hard. This dyad considered whether a good-health lifestyle is easy or hard. Many suggested that a good lifestyle is actually easier.

Living healthy is best and easier than bad choices. (Participant ♂ G.)

Proposed future research approaches included photovoice and body mapping to identify positive lifestyle choices facing Aboriginal youth.

Module 4. Capturing attitudes towards self and health is complex. Through the guidance of the Elder–youth dyad, participants visualized things/people/times associated with when they were the most well. These visualizations were then depicted on ceiling tiles, which often featured

- bright and primary colours;

- the outdoors/scenery, including the sun;
- groups of friends/family and play activities; and
- use of Dakota language in relation to sacred teachings.

Participants stated they tried to capture warmth, hope, joy, and feeling free and safe.

I drew lots of green grass and blue skies ... the Creator expects us to take care of the earth so we all live happy. (Participant ♀ M.)

My family and friends make me happy and safe ... at a feast with lots of food and games. (Participant ♀ T.)

Future recommended strategies included vignettes by Elders and youth about positive attitudes, performance theatre (Prentki & Preston, 2008), and personal “bumper stickers” capturing positive attitudes.

Module 5. Embodiment of beliefs and cultural lessons was critical to understanding and uptake as “it is in these (activities) that our spirits/Spirits soar” (Angelo Wasteste, personal communication, February 10, 2012). Evidence of engagement and mobilization of participants included:

I never thought much about why a skirt [, it actually just seemed silly, but now I know how it is respectful and how lucky I am to be a part of ceremonies. (Participant ♀ N.)

We learned about the games and hear about the games , but it was strange to find out that some games were to teach us lessons on math and sciences. (Participant ♂ A.)

Conclusion

Increasingly, there is recognition of the need for wise practice approaches, such as **PL³A³Y**, to improve and sustain cultural, social, and personal prospects of Aboriginal youth. Whether encouraging positive lifestyles to reduce self-destructive behaviours (Warry, 2009), or establishing asset-based initiatives to build self-confidence and self-esteem (First Nations Recreation Guide, 2003), Aboriginal youth participation and inclusive decision making is necessary for building wise practices. CBPR as a research methodology removes the current pathological approach to wellness and instead inserts a strength-based approach that respects Indigenous knowledge.

Shaid, Durey, Bessarab, Aoun, and Thompson (2013) reflected on how members of Aboriginal cultures communicate differently than mainstream society; hence, the project’s use of oral tradition (stories, games, role modelling) and hands-on interactive learning (visualization, mirrors) was appropriate. Little Bear (2000) found group mentoring to be an effective strategy for Indigenous youth, as reflected by **PL³A³Y**, with youth mentoring younger community members and Elders mentoring youth. The role of youth in developing culturally and socially

relevant programs through this initiative was highly empowering, aligning with similar findings by Kelly's (2007).

Based on lessons learned in this research and by others (Jardine & James, 2012; Mason & Hood, 2011), there is an opportunity and imperative to engage and embed youth more directly in the research process. Yet, there is a significant learning curve requiring thoughtful and inclusive efforts by academics, community leaders, and youth. Interventions to support youth through adolescence can have lasting positive impacts on physiological, psychological, and social functioning of the individual *and* the community (Wolfe, Jaffe, & Crooks, 2006). Anecdotally, it was interesting to note that the Grade 12 completion rate amongst Aboriginal students in Saskatchewan is 32.7% compared to 72.3% for all students (Government of Saskatchewan - Saskatchewan Education, 2011); however, of the cohort of students involved in this project, 100% graduated. Further, three of the six research assistants have gone on to postsecondary education. In addition, the school at Standing Buffalo has continued to use products developed in the Culture Camp within the curriculum. This has led to an increased interest in traditional games, and increased understanding of cultural values, language, and ceremony.

Health and social challenges facing Aboriginal people, generally, and Aboriginal youth, specifically, are numerous; hence, efforts to reveal preferred futures are instructive. Empowered and engaged youth are imperative to normalizing positive outcomes for the next generations, potentiating decreased health disparities and healthier communities. With continuing efforts to encourage and support Aboriginal youth to understand, participate, and lead, they will **PL³A³Y IT FORWARD!**

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The Impact of Historical and Current Loss on Chronic Illness: Perceptions of Crow (Apsáalooke) People

Abstract

The purpose of this research was to gain a better understanding of perceptions about the impact of historical and current loss on Apsáalooke (Crow) people acquiring and coping with chronic illness. This study took a qualitative phenomenological approach by interviewing community members with chronic illness in order to gain insight into their perceptions and experiences. Participants emphasized 10 areas of impact of historical and current loss: the link between mental health and physical health/health behaviors; resiliency and strengths; connection and isolation; importance of language and language loss; changes in cultural knowledge and practices; diet; grieving; racism and discrimination; changes in land use and ownership; and boarding schools. The findings from this research are being used to develop a chronic illness self-care management program for Crow people.

Keywords

Historical trauma, chronic illness, chronic illness self-management, American Indian, Native American, Crow Nation

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Introduction

The Community

The Crow Reservation is located in the northwestern United States, in southeastern Montana, bordering Wyoming on one side. The Apsáalooke or Crow people have lived in this area for hundreds of years (Medicine Crow, 1992; Old Coyote et al., 2003). The Crow Reservation has high rates of chronic illness and unemployment (Montana Department of Public Health & Human Services, 2011). Members of the Crow Nation have also been subject to a long

history of trauma and discrimination, yet they have survived and continue to hold traditional practices and values.

Colonization Experiences

The first official relationship between the United States government and the Crow Nation was in 1825 in a friendship treaty that was meant to establish relationships and allow for protection to settlers moving into the area (Loughman, 2002; Medicine Crow, 1992; Old Coyote, Old Coyote, & Bauerle, 2003). The Fort Laramie Treaty of 1851 established the boundaries of the first Crow Reservation. This treaty was also meant to provide supplies and rations for the Crow people; however, these were often spoiled, inadequate, or not received at all (Loughman, 2002; Medicine Crow, 1992). Through treaties, Crow land was reduced from 38 million to the current 2.25 million acres (Loughman, 2002; Medicine Crow, 1992; Old Coyote et al., 2003).

Through all of this, the Crow Nation worked to maintain friendly relations with the United States government. Crow chiefs spoke at a Peace Commission in 1867 at Fort Laramie (Oman, 2002). In the commission, the chiefs talked about the kindness and peacefulness that they had shown to the white men who had been through their area. They shared that they were not returned the favor and had been shot at by white men (Loughman, 2002).

In 1868, the Crow signed the second Fort Laramie Treaty (Loughman, 2002). This treaty confined the Crow to the reservation and placed them under stricter control by the government. The Indian agents assigned to the Crow Reservation tried to change the Crow people from their nomadic lifestyle to a farming lifestyle by limiting their hunting rights and pressuring them to establish permanent dwelling places (Graetz & Graetz, 2000). Joseph Medicine Crow (2006) described how a Crow elder shared that this change hurt the hearts of the Crow warriors. After the Crow Agency government boarding school was opened in 1883, parents were required to send their children to the boarding school or be denied their rations. Also in 1883, the first Crow child was sent to board at the Carlisle Industrial School in Carlisle, Pennsylvania (Montana Office of Public Instruction, 2010).

Chronic Illness

Chronic illnesses are defined as long-term illnesses with no known cure that often result in negative health outcomes such as preventable death, disability, lower quality of life, and greater healthcare cost (Centers for Disease Control and Prevention, 2014). High rates of chronic illness plague the United States. Of the top 10 causes of death across the country, seven are chronic illnesses (Heron, 2013). American Indians have among the highest rates of any population for some chronic illnesses (Gallant, Spitze, & Grove, 2010). Not only do American Indians have high prevalence rates of chronic illnesses, they are also more likely to die earlier from them. In Montana, American Indians die on average 14 years earlier than their non-Indigenous counterparts from heart disease, 12.5 years earlier from diabetes, and 11 years earlier from cerebrovascular disease (Montana Department of Public Health & Human Services, 2013).

Historical and Current Trauma

Historical trauma can be defined as a traumatic event or set of events that have been committed by a group in control against a group of people who were not in control (Walters et al., 2011). A variety of terms are used to describe the outcomes of these events, such as “soul wound” and “historical loss” (Duran, 2006; Whitbeck, Walls, Johnson, Morrisseau, & McDougall, 2009; Yellow Horse Brave Heart, 2003). For this study, community members stated that they preferred “historical loss”. Walters et al. (2011) explored ways these terms have been used and applied in the research and theoretical literature. They organized the uses of the terms into four categories: as an etiological agent, as a particular response or syndrome to the etiological agent, as a pathway to transfer trauma across generations, or as a stressor that interacts with current trauma and stress (Walters et al., 2011). For the purposes of this study, we are using the term to refer to an etiological agent. We include events that occur at both the community and individual levels as well as events that have happened in the past and that occur in the present. For example, land loss through treaties has an impact at the individual level for the family or individual who lost land and also at the community level, through the signing of treaties and the establishment of reservations, which has an impact on the lifestyle of the tribe. There are multiple examples of trauma that occurred historically and continue today, including language loss and racism.

This paper will explore perceptions of the link between chronic illness and historical and current loss among members of the Crow Nation. We have not seen this link investigated in the existing literature, but an understanding of it is vital to developing culturally consonant programs to improve chronic illness management.

Relationship

This research was conducted through the Messengers for Health program, which began in 1996 as a partnership between the Crow Nation and Montana State University. A community-based participatory research (CBPR) approach was utilized, led by a community advisory board. The board began informally in 1996, was formalized in 2001, and has actively sought solutions to health disparities since. The nine members of the community advisory board are all enrolled members of the Apsáalooke Nation.

CBPR is a collaborative research process between researchers and community members. Through this community-based process, the partners decided to develop and test a translational intervention research project to improve chronic illness management with and for members of the Crow Nation. The community advisory board and the research team wanted to develop an intervention based on cultural strengths that exist within the community. In order to base the project in cultural strengths, it was important to gather information from the cultural community members who are currently coping with chronic illnesses (Christopher et al., 2011; Israel, Schulz, Parker, & Becker, 1998; LaVeaux & Christopher, 2009; Wallerstein & Duran, 2006).

Methods

To understand what facilitates and hinders chronic illness management, 20 exploratory qualitative interviews were conducted with American Indian men and women on the Crow Reservation who have a chronic illness diagnosis. We received Institutional Review Board approval from Little Big Horn College, which is the tribal college on the Crow Reservation.

Alma McCormick, a Crow tribal member and executive director of Messengers for Health, conducted the interviews. Alma has a long history of conducting interviews in the community and has research ethics training through the National Institutes of Health Collaborative Institutional Training Initiative. There are a number of advantages to having a community member conduct the interviews, including comfort level of the participants (Christopher, Knows His Gun McCormick, Smith, & Christopher, 2005). Participants were able to set up a time and location that was convenient for them and were interviewed in their home, at the Bighorn Valley Health Center (BVHC), at a conference room in the local library, at the Messengers for Health office, or at the interviewer's home. BVHC is a community healthcare center that is focused on the needs of the residents of Big Horn County and is a community partner in our research.

A mixed methods sampling strategy was used, including a criterion strategy, and an opportunistic approach. The criteria for participating were as follows: (a) a patient of BVHC, who has (b) a diagnosed chronic illness, and who has been (c) identified by the staff at BVHC as an individual who could provide information on their experience of having a chronic illness. BVHC staff referred these individuals to the interviewer. There were 13 patients who were referred in the criterion process. The opportunistic participants were either self-referrals who saw recruitment material for the study at BVHC and contacted the interviewer, or were BVHC patients who were referred by participants recruited through the criterion process. There were four self-referral participants and three participants who were referred by other participants.

The participants were given the option to share their name or to remain anonymous; five participants chose to remain anonymous and 15 participants waived their anonymity. As discussed by Shawn Wilson (2008), many Indigenous communities believe that a person should be credited for their words and so we wanted to provide the participants this option. Participants ranged in age from 26 to 78 with an average age of 52. There were eight male participants and 12 female participants who had a variety of chronic illnesses including hypertension, chronic pain, chronic persistent hepatitis, chronic obstructive asthma, diabetes mellitus, hypertension, chronic kidney disease, alcoholic cirrhosis, and rheumatoid arthritis. Most of the participants had more than one chronic illness. Interview lengths ranged from 9 minutes 33 seconds to 1 hour 40 minutes 32 seconds, and the average length was 42 minutes and 3 seconds.

The interview questions were open-ended. This paper will focus on those questions that addressed perceptions of the impact of historical and current loss on acquiring and coping with chronic illness. For the purposes of this research, we used the term "historical loss" in the interviews instead of "historical trauma," as our Crow research partners stated that "historical trauma" is considered an academic term while "historical loss" was more relatable. The research

team also felt that it was important to include the effects of current loss, such as language loss and racism. Additional questions not explored in this paper focused on the participants' experience managing their chronic illness and their thoughts on what should be done to help chronic illness patients on the reservation.

The questions related to historical and current loss were as follows:

- In what ways do you think historical and current losses such as land loss, broken treaties, boarding schools, language loss, and racism have had an effect on the health of our people?
- In what ways do you think these historical and current losses have affected people getting chronic illness?
- In what ways do you think these historical and current losses have affected people coping with chronic illness?

Analysis

All interviews were transcribed verbatim. The three questions were analyzed without software using thematic content analysis. The content analysis process is used to review the interview data and to develop themes (Creswell, 2014). For our process, the first, second, and fourth authors read the responses to the three questions and developed an initial list of themes. The fifth and sixth authors joined in a discussion to develop a final list of themes and subthemes, which the first author then used to code all of the transcripts. The fourth author then randomly coded 10% of the interview transcript pages, which were compared with the first author's coding. Coding differences were discussed and a consensus process was used to develop a final list of codes. The first author then re-reviewed the transcripts for any additional or missed themes. Analysis of these questions and others was also conducted with the community advisory board and project staff using culturally appropriate methods (Hallett et al., 2016).

Results

Areas of Impact of Historical and Current Loss

When the interviews were read, we noticed that participants discussed similar responses across the three questions. Therefore, we analyzed the interviews across the questions rather than analyzing separately by each question. The following 10 areas of impact of historical and current loss emerged in the content analysis, presented in order of highest to lowest prevalence:

1. Link between mental health and physical health/health behaviors
2. Resiliency and strengths
3. Connection/isolation
4. Importance of language/language loss
5. Changes in cultural knowledge and practices
6. Diet

7. Grieving
8. Racism/discrimination
9. Changes in land use and ownership
10. Boarding schools

These areas of impact are discussed below. Quotes are shared to illustrate each area, including information on the quoted participants' gender, approximate age, and chronic illness(es).

Link between mental health and physical health/health behaviors. When sharing information on how historical and current loss have affected health, a large number of participants discussed the connections they saw between mental health factors and physical health or health behaviors. Mental health factors included stress, grief, depression, inability to forgive, bitterness, and resentment. They saw these mental health factors as leading to or causing physical health outcomes, including disease in general and specifically diabetes. They also saw the mental health factors causing health behaviors including self-medication and substance use and abuse. Many of the participants talked about stress and depression and how they impact the body. This participant mentioned how losses contribute to mental and physical health:

They just seem to not care anymore. You know ... like take care of themselves ... look after each other. ... I think that's because of all that [the losses], they've ... just kinda lost interest. (Female, 50, chronic pain syndrome, hypertension)

This participant commented on losses and how they led and lead to depression and other diseases:

They took a lot away, all within a short period of time. And it was a whole culture shock and I think that made a lot of people depressed ... it leads to other diseases. That's my belief. (Male, late 30s, hypertension and diabetes)

Resiliency and strengths. When the participants were asked about historical and current loss, some brought up the issue of survival. Participants described genocide and how American Indians have survived the multitude of genocidal acts that have been committed against them. They discussed specific acts against their tribal nation and acts committed against tribal nations in general. They shared specific strengths that American Indians, and Crow people, developed in response to historical and current trauma, including seeking knowledge and strength in general. This participant, and others, described a general strength that came out of surviving genocidal acts:

I think it affected them [Crow people] right away, but I think we learned to get strong and to just to be strong. It really made us strong in the mind and in the soul. (Male, late 30s, hypertension and diabetes)

Connection/isolation. One impact of historical and current loss mentioned by many participants was connection, disconnection, and isolation. Participants talked about the importance of traditional practices of visiting and connecting as families and as a tribe. Many specifically mentioned that the decrease in these practices was due to changes in the social and political structure of the community as a result of colonization. One participant shared:

People are going distant from each other ... where it used to be, everybody used to, like, get together. (Female, early 50s, chronic pain syndrome, hypertension)

Importance of language/language loss. When answering questions about the impact of historical and current losses, participants talked about feeling frustration over the loss of language and a personal desire to know more of the language if they did not speak it. Participants also felt that the Crow people are lucky to have their language to the degree that they do. The loss of the language for some is connected to historical trauma that occurred in boarding schools and other assimilation policies and programs that impacted Crow people. One participant expressed this sentiment:

And we speak to them in Crow; they don't even know what you're saying anymore. And that's a big loss. And now the Crow language has completely changed from the old Crow language. (Male, early 50s, chronic pain syndrome)

Another participant shared:

When we go away to school, they tell us not to speak the Crow language ... because they, the English people that don't speak the Crow language, feel offended. And they feel that we should not speak our own language, but to always speak English. And so that takes some of the feeling we have—how proud we are of our language, it takes it away. ... And this is offending our whole body system. Because I feel it's a part of our life. (Female, late 70s, chronic kidney disease, diabetes mellitus)

Changes in cultural knowledge and practices. When asked about the impact of current and historical loss on health, participants discussed the loss of traditional practices, traditional medicine, and traditional activities. Participants discussed changes in communication patterns and relationships between older and younger generations and a negative change regarding role models. In the past, role models were people within the community, and now many role models are people outside of the community. Participants also discussed a decrease in tribal activities such as powwows and hand games. Finally, participants talked about changes in tribal political structure. They talked about how the past coup system, of chiefs being chosen based on their action in battle, is vastly different from the current political structure of voting for tribal leaders. Participants drew a connection between these changes and colonization experiences. We share two examples:

It's very important to have all of your cultural beliefs and customs intact. Makes a whole person. Otherwise you're missing something. (Male, early 50s, diabetes mellitus, hypertension)

They wanted assimilation of the people, and they're doing that. They're trying to get them to be completely where they're off the reservations and no longer part of their culture. (Male, late 50s, chronic persistent hepatitis)

Diet. Many participants discussed diet in response to questions on how historical and current losses affect health and getting and coping with chronic illness. There was talk about changes in access to traditional foods and lack of current access to healthy foods. There was discussion about the introduction of novel foods to Crow people and commodity foods. Commodity foods are those that are provided to American Indians through the federal Food Distribution Program on Indian Reservations. Participants commented that foods are often considered to be very low quality. This participant commented on commodity foods:

The commodities and all the corn syrup they fed us through our lives. That's got all the sugar, diabetes and stuff. Yeah. All the grease. They used to give us lard. White lard. I remember that ... white lard, gallon buckets of it ... that's what we cooked with, baked with. So you think about the fat in the hearts of people. The government—yeah. (Male, mid-70s, diabetes mellitus, hypertension)

Grieving. Many participants talked about historical and continuous and ongoing loss and the difficulty of overcoming that loss. Losses included death in families and the community, and there was also discussion of children who were removed from their families. Content under this area of impact crosses over into many of the other areas. One participant commented:

You know, when a family loses their loved ones, it's like they just give up on life, and its um, seems like they don't care. (Female, early 60s, diabetes mellitus)

Racism/discrimination. When asked about the impact of historical and current loss on health, participants discussed the impact of past and current racism and discrimination. This included racism that took place in medical, institutional, and governmental settings. There was discussion of the white man having power and of feelings of helplessness, injustice, and anger at being cheated. Participants also described the impacts of acts of genocide that were committed against American Indians. For example:

We were promised one thing. It was a lie. And we're affected by it today. (Female, late 40s, diabetes, chronic kidney disease, chronic pain)

This participant discussed current mistreatment by the government and its consequences:

It's terrible, the way they treat the people, and it's there today. You see it. You hear about it. Causing a lot of grief on a lot of people. They're wondering what's gonna happen, and you know, I think the ... government hasn't left the Indians alone yet today. They're still out there tormenting and taking the land from us, and doing what they damn well please. (Male, 50, chronic pain syndrome)

Changes in land use and ownership. Participants' responses to how historical and current loss affect health included past, current, and future changes in land use and land loss. This included reservation-era land loss, land loss and mismanagement by the Bureau of Indian Affairs (BIA) that is happening now, and anticipated land loss through future governmental acts. Participants talked about different uses of the land, and land being sold for money, for example:

All the good land is bought up by the white man ... the white man's taken everything that was really needed by the Indians. ... That superintendent of BIA just step in there and say, "Well, I can take this land back from you." And I had to turn it over to this white man. (Male, mid-70s, diabetes mellitus, hypertension)

Boarding schools. There were stories of personal experiences in boarding schools, and participants who talked about the lasting effects of boarding schools, including cycles of abuse. Crow children were like many other Native American children and were sent across the country to boarding schools. In later times there were also religious boarding schools and mission schools. Both the boarding schools and the mission schools were reportedly places of abuse. A participant shared:

And they sent me off to school. And I didn't want to leave my brothers and sisters because I loved them so much. But they sent me off to school, and what could I do but go. (Female, late 70s, chronic kidney disease, diabetes mellitus)

Discussion

Participants felt that there were historical and current losses that impacted the development and management of chronic illness among Crow people. There were many strong first reactions to the question of how historical and current losses have affected health, including: "It's affected the tribes tremendously," "It's made a huge impact," "Oh my goodness," and "Oh gosh, how could you ever get me started on that?" Many participants shared information from a broad perspective rather than describing a linear relationship between cause and effect.

These interviews were conducted to assist in the development of a chronic illness self-care management program for Crow people. Chronic illness self-care management includes the daily steps and choices individuals make to manage their chronic illness (Center for Managing Chronic Disease, 2011). There are various self-care management programs in existence; however, most programs were developed from a majority Western cultural lens and may be

inappropriate to be applied in an Indigenous setting (Castro, O'Toole, Brownson, Plessel, & Schauben, 2009).

The information shared by participants led our team to underscore the importance of addressing the impact of historical and current loss in the development of our chronic illness self-management intervention. Warren, Coulthard, and Harvey (2005) saw a similar need when they applied a Western-developed chronic illness management program with Aboriginal people in Australia. The program they were applying did not address grief and loss, and they stated that participants had grief and loss issues that were vital for them to address before they could focus on chronic illness management.

As the questions we asked were about the effect of current and historical loss on chronic illness, many of the responses, and thus the areas of impact, reflect deficits. We believe that directly addressing the impacts of trauma validates community members' experiences and difficulties and helps to initiate the development of healthy coping strategies. The intervention that we are developing based on the interviews uses key aspects of trauma-informed interventions, such as promoting a sense of safety, calm, self- and collective efficacy, connectedness, and hope (Elliott, Bjelajac, Falot, Markoff, & Glover Reed, 2005; Hefferon, Greal, & Mutrie, 2009; Hobfoll et al., 2007), along with community cultural strengths such as the language (*biiluukeilia*), clan system (*ashamaliaxxia*), a strong heart or resilience (*dasseitchiachuchek*), provision of advice and instructions for life (*baa nnilah*), and spending quality time with others (*itchik dii awa kuum*). Using these strengths creates a comfortable and safe place that allows information to be absorbed and encourages confidence in community members' ability to take action toward better health. Respecting cultural values creates a comfortable atmosphere to share information and feelings, which promotes growth and strengthens resilience. We believe that unearthing these deficits and addressing them with community strengths is a necessary step toward community healing.

Limitations

Several aspects limited this study. The interviews were conducted in English for the convenience of the university partners. For some of the participants, Crow is their first language and it would have been more comfortable for them to speak Crow. Our interview questions were focused on perceptions of the effects of historical and current trauma, rather than asking more direct causal questions. We chose to ask the questions in this way to be respectful and to aid in the development of a community-based intervention to improve chronic illness self-care. In this analysis, we were limited by the fact that we broke apart the interviews by conducting thematic analysis instead of keeping the stories whole (Kovach, 2010; Wilson, 2008). Our reason for this was that we were looking at only a few of the interview questions that were specific to historical trauma. Also, in our analysis, we did not focus on the connection between responses and gender or chronic illness condition. This was because our aim was to develop an intervention that could be applicable across the community.

Conclusion

Many Crow people perceive that historical and current loss has had an impact on their lives, especially in the areas of developing and managing chronic illness. In partnering with chronic illness patients in developing an illness management program, it is important to develop a component that will directly assist with impacts of historical and current grief and loss.

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Our Way of Life: Importance of Indigenous Culture and Tradition to Physical Activity Practices

Abstract

To challenge the current negative and disease-oriented view in the Western health science paradigm, researchers from the University of Alberta collaborated with the Yellowknives Dene First Nation's Community Wellness Program in a participatory action research project that took a wellness- and strengths-based approach to explore physical activity. We worked with youth to develop participatory videos about physical activity, which sparked community conversations on health promotion, community wellness, and ways to encourage more people to engage in physical activity. Findings revealed a multifaceted meaning of physical activity, supported by the theme of cultural identity. Participants highlighted aspects of culture, tradition, participation, and the land in defining physical activity. Being active was not only about soccer and running, but also playing traditional games, checking the fishnet, scraping the hide, being out on the land, and participating in the community. In other words, to be physically active was to be culturally active and to actively contribute in the community. Ultimately, through collaboration and dialogue, we generated different meanings of physical activity grounded in wellness, and we reinforced and provided further understanding of the cultural element of this health science terminology in an Indigenous context.

Keywords

Physical activity, participatory action research, participatory video, youth, cultural identity, strengths-based approach

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Introduction

Diverging Views of Health

Achieving adequate levels of physical activity, a popular health promotion focus (Findlay & Kohen, 2007), is often seen as a disparity that puts Indigenous people at risk for obesity, diabetes, and cardiovascular diseases (Lee et al., 2012; Miles, 2007; Young & Katzmarzyk, 2007). This disease-focused health paradigm contrasts drastically with the more holistic Indigenous view of healing and wellness. Some authors identify this divergence in worldviews as a major reason for the limited impact of health promotion interventions in Indigenous communities (Adelson, 2005; Findlay & Kohen, 2007). Whereas the biomedical paradigm often views health as a personal responsibility and concepts such as physical activity as prescriptions to reduce disease risks (Petersen, Davis, Fraser, & Lindsay, 2010), Indigenous worldviews situate health as relationships with self, others, the community, and greater cosmos (Lavallée, 2007). Individual health and wellness are intrinsically related to collective well-being and identity (Kirmayer, Simpson, & Cargo, 2003), achieved through the balance of body, heart, mind, and spirit. Health and wellness are thus conceptualized more broadly as an interconnection between physical, mental, emotional, and spiritual components (Graham & Leeseberg Stamler, 2010; Lavallée, 2007).

To challenge the current negative and disease-oriented view in health sciences, researchers from the University of Alberta and the Yellowknives Dene First Nation (YKDFN) in the Northwest Territories (NWT) took a wellness- and strengths-based approach (Paraschak & Thompson, 2013) to explore physical activity. We carried out a participatory video project as a health promotion intervention to comprehensively understand the meaning of physical activity within the larger community context and encourage more people to be active.

Relationships

The strengths-based approach in this project aligned well with the interests of the community and the researchers. After a summer participatory video project with youth about smoking prevention led by the third author of this paper (Genuis, Jardine, & Chekoa Program, 2013), the YKDFN Community Wellness Program (CWP) was keen on continuing similar projects. Through my supervisor (Jardine), I¹ connected with CWP as a research partner on this

¹ In this paper, first person plural “We” indicates the partnership between the community partner and the researchers, and the singular “I” refers to the primary researcher (first author).

project and directly worked with a research liaison. We identified physical activity as the research focus for exploration through ongoing discussions during my regular visits to the community. In those early conversations, CWP emphasized that the traditional Dene way of life is inherently physically active. This cultural perspective grounded the research from the start and allowed us to integrate the project as part of the summer youth cultural camp program. We continued to work collaboratively in designing the research project, analyzing data, and organizing knowledge translation activities.

Theory

The concept of critical consciousness, developed in the 1970s by the Brazilian adult educator Paulo Freire (2000, 2005), profoundly influenced this research. Freire believed that conscientization, or consciousness-raising, leads to people taking actions. In other words, as people critically examine their experiences, they develop meaningful solutions or actions to better their social, economic, and political realities (Wallerstein & Duran, 2008). Unlike conventional research, communities participate actively in a process known as *praxis* that cycles between reflection and action (Freire, 2000). Instead of imposing their views on the community, researchers assume the role of facilitators to promote collective reflection and social action, with a strong belief that change must come from within (Wallerstein & Duran, 2008).

Methods

Research Approach and Methodology

Often grounded in critical consciousness, participatory action research (PAR) directly engages the people that the research is meant to affect (Cargo & Mercer, 2008). Research is done with participants, rather than on or to them (Frisby, Reid, Millar, & Hoerber, 2005). The approach is highly reflexive, centering on collaboration, inclusive and safe spaces, and balanced power dynamics (Cargo & Mercer, 2008). The CWP and I took a collaborative approach throughout the process. In each phase of the project, we engaged in constant discussions to make joint decisions on an appropriate and relevant research approach, interpretation of the results, and subsequent actions.

Applying Indigenous Research Methodology in a Participatory Inquiry

This PAR project was situated within the specific context of Indigenous Peoples and was undertaken in collaboration with communities. The research was informed by an Indigenous research methodology (IRM; Wilson, 2008) and maintained an orientation that respects Indigenous worldviews and knowledges. Understanding that I am not an Indigenous person, I was careful not to re-appropriate IRM. Instead, I strove to learn about and practice principles of IRM in a respectful way, constantly recognizing the root of the knowledge.

Some Indigenous researchers also see PAR as compatible with IRM because it “facilitates Indigenous peoples’ ownership, control, and access to the re-search² process” (Absolon, 2011, p. 30). In this particular research, specific methods such as participatory video were selected in a collaborative and open process, and aligned with Indigenous understandings and ways of knowing through visual and oral representations. Prioritizing Indigenous ways of knowing and equal community participation integrates the strengths found in both Indigenous and Western knowledges, consistent with the “two-eyed seeing” approach (Lavallée & Lévesque, 2013).

IRM promotes the values of respect, relevance, reciprocity, relationality, and responsibility (Hill, 2008; Weber-Pillwax, 2001) to ensure the integrity of research. These teachings are manifested when researchers situate themselves from the start, form relationships with the community, participate in the community to give back, honour community’s knowledge by prioritizing its desires rather than imposing outside values, and ensure research is always relevant to the people. In this project, the CWP’s vision of traditional physical activity led the research, underpinning the entire process with a fundamental cultural element, as well as the community’s definition of health and wellness in terms of mental, emotional, spiritual, and physical.

With an open mindset, we aimed to keep the project holistic in two ways: (1) supporting participants’ self-directed exploration of physical activity in ways that were meaningful for them, and (2) constantly prioritizing local and traditional knowledge. Not prescribing what physical activity meant aligned with the idea of non-interference (Brant Castellano, 2004), which respected Indigenous knowledge and self-determination. Early conversations with the CWP framed physical activity within a cultural and land-based definition. This starting point significantly shaped how participants interacted with the research topic and the findings they generated.

Data Generation Overview

Through ongoing dialogue with the CWP and based on community interest in a summer video project, we selected four methods to generate data:

1. Participatory videos created by youth were the primary mode of data generation ($N = 19$ youth). Unstructured interviews with the youth provided further information about the process and their video products.
2. Community focus groups elicited diverse perspectives on the videos and people’s lived experiences with physical activity ($N = 11$ participants).
3. Semi-structured interviews with community members and leaders allowed these individuals to evaluate the impact of the research and activities following the project ($N = 9$ respondents).
4. Research journals, which included participant observation, field notes, summary of dialogues, and reflections, served as the last means of data generation. These journal entries were recorded from the researcher’s perspective and did not directly involve any participant.

² Absolon (2011) defines *re-search* as searching again, a personal process of “preparing, searching, and making meaning” (p. 32).

Ethical approval for the research was received from the University of Alberta's Human Research Ethics Board (REB 1). A research license was obtained from the Aurora Research Institute to conduct the research in the NWT. Adult participants in this project provided consent, while youth under age 18 provided assent and further received parental consent. Nonparticipants appearing in the final videos provided permission to use their images. The names of youth and community members have been anonymized to respect participant confidentiality. However, given PAR's emphasis on human agency, youth retained the film credits and community information in the final videos to acknowledge the video makers. The line between confidentiality and honouring the sources of information is a constant tension in Indigenous research (Ermine, Sinclair, & Jeffery, 2004). Ultimately, we believed that it was ethical to respect the decisions of the participants and the community.

Youth participatory videos. Grounded in Freire's critical consciousness theory, participatory video is an increasingly popular visual research tool, which couples video making with democratic participation to spark reflection (Low, Brushwood Rose, Salvio, & Palacios, 2012). It is a "set of techniques to involve a group or community in shaping and creating their own film" (Lunch & Lunch, 2006, p. 10). Not only does this method align with the oral tradition found in many Indigenous cultures (LaFlamme, Singleton, & Muir, 2012), it also elicits voices that may otherwise remain silent through conventional means of data collection (Liebenberg, Didkowsky, & Ungar, 2012). Previous experience in the same community demonstrated that youth-developed messages were a powerful means of health promotion and communication (Jardine & James, 2012). Further, by focusing on their voices, we engaged young people as community resources, consistent with our strengths-based approach.

For three weeks in 2013, we worked with 19 YK Dene³ youth aged 8–18 years to create participatory videos portraying physical activity in the community and on the land. Seven boys and 12 girls were recruited through convenience sampling (Côté-Arsenault & Morrison-Beedy, 2005; Ford & Beaumier, 2011): CWP staff recommended some youth who were interested and available while others participated through word of mouth.

During the first week, I facilitated video-making workshops in the community where youth familiarized themselves with video equipment and editing software. They developed their capacity in digital media and research by exploring the question "What is physical activity?" through filming videos in their immediate surroundings. Youth continued producing videos during the second week of the project, at the cultural camp on the land. The summer cultural camp is an annual community event organized by the CWP, teaching youth on-the-land practices and skills. In the third week, youth returned to the community and edited the films. We stored the footage on community computers, underlining community ownership of the data and providing youth the option to make more videos in the future.

Throughout the process, I engaged youth in ongoing conversations about their lived experiences with and perspectives on physical activity. These conversations followed an overall

³ Community members from YKDFN self-identify as YK Dene people. Most of the members reside in two communities of a few hundred people.

ORID structure (Stanfield, 2000): Objective (What do you know?), Reflective (What do you feel?), Interpretive (What does this mean?), and Decisional (What do we do?). In this last Decisional stage of ORID, youth shared ideas to encourage greater participation in physical activity in the community.

With permission of the youth participants, their final videos were produced on DVDs that could be distributed back to community members and others, and posted on YouTube for more widespread availability (www.youtube.com/user/ykdenewellness).

Community focus groups. The videos sparked conversations in the community. Eleven community members and leaders (eight women and three men), recruited through convenience sampling (Côté-Arsenault & Morrison-Beedy, 2005; Ford & Beaumier, 2011), participated in focus group discussions. Most of the participants worked in some capacity within the community. They ranged from a youth who facilitated recreation activities to an elder who was the community counsellor. During this phase of the project, participants analyzed the videos, linking images back to their own experiences and reflecting on the challenges and realities of organizing community-level physical activity initiatives. Like conversations with the youth during video making, these focus groups followed the ORID structure (Stanfield, 2000), and participants brainstormed more actions to promote greater community participation in physical activity.

Knowledge translation. The CWP and I shared knowledge generated from the project with community members at two community family suppers. We presented the videos and other research findings, distributed the DVDs, celebrated youth initiative in the video project, and promoted active living through games and a family quiz. We also shared the various physical activity ideas generated by the youth and the focus group participants throughout the research. At the end of the night, community members voted for their favourite new community physical activity programs from this list of ideas. Aligning with PAR principles, this community vote was important to the process of collective decision making that prioritized initiatives for the CWP to incrementally implement in the next few years. Sports tournaments, traditional games, and community hunts involving youth were the most popular ideas.

Follow-up evaluation. Several months after the suppers, I returned to the community and evaluated the impact of the research by engaging youth, elders, staff, and community members in semi-structured interviews. Nine respondents—seven women/girls and two men, all with varying degrees of participation in the overall project—discussed their impressions of the research and the resulting actions. These evaluation interviews also helped to verify information that strengthened the rigour of the research (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Data Analysis

The data generated by the research were organized by an alphanumeric system based on the participant designations shown in Table 1, which provides a roadmap for the source of data: transcripts from conversations with youth (youth participants Y1–6); finalized videos (V1–8);

focus groups (participants P1–11); evaluation interviews (respondents R1–9); as well as the research journals. Letters and numbers indicate the source of data (e.g., P1 suggests that the quote came from participant 1 in one of the focus groups).

Table 1
Data Generated From the Research and Accompanying Sources

Methods	Data-generating strategies	Transcript codes
1. Video generation	Conversations with youth ⁴	Participants Y1–6
	Videos produced by the youth: <ol style="list-style-type: none"> 1. Activities on the land 2. Summer of Island 3. Cultural camp short clip 4. Things to do at cultural camp 5. Why I like cultural camp 6. Active vs. not active 7. Youth in the community 8. How the community got its name 	Videos V1–8
2. Community focus groups	Focus group discussions	Participants P1–11
3. Follow-up evaluation	Impact evaluation interviews	Respondents R1–9

With support from the CWP, I transcribed all data generated and used qualitative analysis software (NVivo 10) to organize information into preliminary themes and subthemes. The analysis was guided by a conventional qualitative analysis strategy (Hsieh & Shannon, 2005), which involved immersing in the data and repeatedly appraising the codes to abstract themes and subthemes without predetermined notions.

To further strengthen rigour and ensure consistency with the PAR approach, the CWP and I co-analyzed the preliminary coding scheme in a follow-up trip. We had one-on-one conversations that reviewed, checked, and verified each emerging theme and subtheme, characterized by representative quotes. The CWP agreed with, disagreed with, or elaborated upon the characterization. This conversation was audio recorded to facilitate further analysis and writing. The process resulted in the final coding scheme. Later, the analysis was peer reviewed with a university colleague familiar with the community (Mayan, 2009).

⁴ There were 19 youth in total who participated in the video project in various ways – some filmed, some acted, and some edited the footage. Their participation in the overall project resulted in 8 videos that reflected the collective effort. However, only 6 youth specifically participated in interviews that were recorded and transcribed for content analysis. There were ongoing interactions and conversations between the other youth and the researcher as well, but these were not always recorded nor followed the same format as the interviews with the 6 youth. Instead, the informal conversations and interactions were captured through the research journal.

Results

Analysis and ongoing conversations with the community revealed a multifaceted meaning of physical activity, supported by a foundational theme of cultural identity.

Meaning of Physical Activity

Participants conceptualized physical activity as related to movements, an active lifestyle, and traditions. Fundamentally, physical activity was defined as “being active” (V5). Videos, images, narratives, and personal stories generated the following types of activities considered by the participants as being active:

- sports and exercise,
- work and household chores,
- leisure and recreation, and
- culture and traditions.

Youth, in particular, were often quick to associate physical activity with “fitness,” “exercise,” and “the gym” (Y3). These themes were evident in the videos produced by the youth in the community during the first week of the research.

In other cases, physical activity was seen as a broader concept, manifested through being part of the busyness and liveliness of community events (e.g., carnivals, community drum dances): “Everyone was just all moving and doing activities all at once” (P6). Keeping busy also translated into people’s day-to-day lives in the community. The notion of “always doing something” (P7), whether at school, in the home, or at work, was integral to the meaning of being active.

Further discussions layered notions of participation in community activities onto this foundational understanding of physical activity. This concept was evident in the videos from the cultural camp, which recorded activities on the land such as checking fishnets (V3), cutting caribou meat, swimming, and peeling spruce (V1). According to participants, being active suggested working and contributing to a greater collective. According to the youth in one video, “Back in the days, everyone was active and they ... always had something to do. Nothing was boring. Boring didn’t exist” (V5). At the cultural camp, chores such as chopping wood, building fires, and hauling water were critical in maintaining the integrity of the camp. Contributing to camp life in any way fostered an inclusive environment, connecting all individuals. One elder reminded us, “There [were] children there, even the little young baby, and also a child⁵, ... a youth, a parent, and an elder. So we’re connected with all the people there” (P1). Thus, at the camp, to participate or to stay constantly busy was indeed being active, whether it was joining others in scraping the moose hide, or chopping up vegetables for supper. Images in the videos portrayed this participatory aspect of physical activity (V1–5).

⁵ Only youth 10 years and older were registered to participate in the cultural camp program. However, families who helped out at the camp also brought other members, including a toddler and younger children who did not participate in the research project.

References to Dene games and ways of life on the land were prominent. Traditional activities are inherently active, a youth explained: “Because we do a lot of movements ... it’s exercising when you do ... chainsaw challenge, or ... leg wrestling” (Y3). Many traditional practices are rooted in survival skills, passed on through generations. For example, the game “stick pull,” where players each pull on a greased stick, is in fact “what makes [people] stronger in catching the fish” (P10). An elder specifically shared teachings about traditional physical activity at the cultural camp, teachings that were internalized by the youth. After the camp ended, a mother discussed her observation about her daughter who participated in the video project:

The kids got to see ... the different movements [at the camp]. ... And ... when [my partner] goes to [chop] the wood, [my daughter says], we did that at culture camp, that’s exercising. You know, she knows it now. (R5)

Her comment highlighted that the cultural camp provided opportunities for youth to more readily link physical activity with cultural activity.

Comprehensively examining the data revealed that discussions about physical activity could be further categorized in terms of spiritual, physical, emotional, and mental health, as defined by this Dene community.

Spiritual health. One focus group participant said, “Each individual there [at the cultural camp has a] relationship with one another, with themselves, with others, with the land. It’s a way of life” (P1). This comment about traditional way of life highlights the interrelationships among all individuals and all beings. This focus on interrelationships alludes to spiritual health.

Physical health. The physical health benefit of physical activity was seen to lie in its disease-preventing ability. Youth participants talked about physical health even if they were unsure of the exact disease: “You have to be active ... so you don’t get ... diabetes or something” (Y5). Youth also linked physical activity to body image: “Because I don’t want to be fat. ... I want to stay healthy” (Y4).

Emotional and mental health. Participants seemed to link the emotional and mental health benefits of physical activity to its confidence-building capacity and the effect it has on one’s mental state. One participant shared her story about accomplishing a challenging physical feat:

We went on a walk two weeks ago ... I was kind of scared because last time, [chest pains, shortness of breath] happened to me. But then ... I walked up there like nothing, walked down there, and it was great! I was OK. We were just walking like it was normal. ... It made me feel good. (P7)

This participant expressed positive emotions while doing physical activity. Another youth pointed out the long-term impact of physical inactivity and an inactive lifestyle on one’s

motivation. If people are not active, she says, “they don’t get any good ... education, or a job” (Y3). Participants also discussed the effect of physical inactivity on mental health:

What the kids are used to, playing games, watching TV, and as they get older into their teenage years ... they get these “lazy minds.” ... I can’t imagine sitting in front of a video game for 8 to 10 hours. ... What does that do to the brain, what does that do to their development? (P6)

Others agreed that sedentary behaviours, particularly those related to screen time or technology use, tended to negatively affect the minds of youth.

Cultural Identity

Embedded in the videos, and throughout the interviews, focus groups, observations, and informal interactions with community members, was the undeniable message that to be physically active is to be culturally active. One participant commented, “The Dene way of life is physical activity; you needed to be fit to be out on the land, and do all this stuff for yourself to survive” (P10). In other words, physical activity is part of the community’s cultural identity, the way YK Dene people live. This theme is therefore critical to the discussion of “what is physical activity,” and what factors encourage or prevent people from engaging in physical activity. Five subthemes supported the cultural identity theme.

Respecting our elders. Youth and focus group participants discussed role models as motivators for physical activity and cultural connection. Elders were frequently brought up as role models for a healthy and active lifestyle and as bearers of knowledge. One participant noted elders’ importance in the community: “If it weren’t for them, for the elders, we wouldn’t be here. That’s why here, we respect our elders” (P4). Another acknowledged, “They’re also active in the community” (P3).

Passing on the knowledge. Participants consistently implied that teaching the next generation is critical in preserving Dene culture and history. One of the important benefits of the cultural camp is transferring the legacies of culture and tradition. One participant voiced, “I think [the cultural camp] is important ... because it’s kind of our tradition to teach young ones about our culture ... Keep it alive” (P9). While the elder played an important role at the cultural camp in teaching knowledge, youth themselves also supported the transfer of the Dene cultural legacy by recording life at the cultural camp. As a result, the video project did not merely promote the summer program itself, but “also promot[ed] the culture” (P3).

Inclusiveness. Participants discussed inclusiveness as part of group activities (e.g., community feasts) and collective identity. Focus group participants suggested that a more accurate portrayal of physical activity would include events with more people. Youth were particularly insightful about how community programs could be more inclusive. One youth shared that only older youth age “10 and up [are] able to go to that [cultural] camp” and that “younger kids” should be included “because they are fun ... [and] funny” (Y4).

Land. Land emerged as particularly important for the Dene people. Not only is it an integral component of cultural camps and other on-the-land programs, it is also related to people's spiritual health and cultural identity. One participant shared:

[The land] makes you feel good about yourself, you just feel alive. ... When I went there [to the cultural camp] ... just for one day ... I liked it, being away. ... It's peaceful out there, just nice. You don't get to do that, like every day ... You take a break from your busy life to go there. (P7)

Many stories and experiences linked physical activity and active lifestyle back to the inherent value of land and traditions.

Traditional practices. In addition to traditional practices portrayed through life on the land, activities such as hand games, traditional game tournaments, and drumming were prevalent throughout the discussions. According to participant 1, the cultural camp program has a deeper meaning that represents the Dene way of life on the land. She explained cultural camp and the importance of the videos:

When we say [cultural] camp ... that doesn't put the meat to it. ... It's just a camp; it doesn't mean a lot. ... Because when it's a way of life ... there's a purpose why [this person is] doing [what he is doing]. ... It's more powerful to say a "way of life." It has meaning to it. Even when ... you show [the videos] to the people in the community ... right there, they'll make the connection with the video. Because they would understand, yeah, that is a way of life. They experienced that ... lifestyle. (P1)

Discussion

In this research, we explored physical activity and its multifaceted dimensions. By understanding how YK Dene people conceptualized and operationalized physical activity, we reinforced this as a multidimensional, cultural concept within an Indigenous health promotion context and sparked community discussions that led to action. The terminology of physical activity was fluid. We came to use it synonymously with active living, traditional way of life, and healthy lifestyle. Culture and traditions grounded all findings. The research process itself shaped conceptualizations of physical activity through reflection among participants and, in the case of the youth, exposure to elder teachings on the value of traditional activities.

Reinforcing Cultural Physical Activity

The meaning of physical activity generated by the participants in this research was comprehensive, with dimensions extending beyond sports, recreation, and exercise. This is consistent with McHugh's (2011) research in which Aboriginal youth felt that physical activity does "not just have to be sports" (p. 14). This research also highlighted the importance of traditional activities in the definition of physical activity, which supports the existing literature on cultural physical activity practices (Giles, 2013; Lavallée & Lévesque, 2013; Paraschak &

Thompson, 2013). Researchers who share this view concluded, “Traditionally relevant [physical activity] opportunities may enhance perceptions of a supportive environment and possibly impact [physical activity] involvement” (Kirby, Lévesque, & Wabano, 2007, p. 6). Moreover, for the participants in our research, physical activity was not restricted to specific activities but spoke to a broader active lifestyle, with participation in and contribution to community livelihood.

As some authors have noted, physical activity is multilayered, complex, and dynamic (Findlay & Kohen, 2007; Thompson, Gifford, & Thorpe, 2000). Lavallée (2007) explored the complex nature of physical activity using the medicine wheel framework, through physical, emotional, mental, and spiritual health perspectives. Other authors have advocated for physical activity “interventions that nurture wholistic health rather than taking a pure problem-based approach to prevention” (Cargo, Peterson, Lévesque, & Macaulay, 2007, p. 102). The words, narratives, and stories shared in this research were consistent with the way this Dene community articulates their overall health and wellness. The results therefore reaffirmed the importance of an Indigenous multifaceted concept of health and wellness as defined by the community, and added to our nuanced understanding of what this means. Moreover, this research underscored the need for youth and communities to specifically recognize and articulate their own understanding of health and wellness, in keeping with critical consciousness theory.

Our research also distinguished viewpoints from different generations. For example, conversations with youth and adults differed on who is physically active and what is physical activity. While many adults spoke outright about elders as role models for physical activity, the youth did not directly make the association. Furthermore, in defining physical activity, youth appeared to initially compartmentalize activities that were physically active and those that were strictly cultural. This finding about youth’s contextual understanding of physical activity resonated with the idea that “sports, recreation, physical activity, and active living are culturally and historically confined” (Giles, 2005, p. 49). Ultimately, the link between being physically active and culturally active became a key lesson that the youth learned during the research process.

Research to Action

A key component of this research process was stimulating critical reflections on physical activity within the community and identifying opportunities for action. The community prioritized six actions—walking marathons, Biggest Loser weight loss challenges, community hunts, longer and more inclusive cultural camps, sports tournaments, and traditional games. The CWP continues to incorporate these actions in its program planning in ways that are feasible and meaningful for the organization and the community. Follow-up conversations with CWP staff and community members demonstrated that small changes based on the results of this research had already happened. The cultural camp in the year following the research was inclusive of families. The CWP continued with the traditional physical activity teachings from the elder at the camp and added daily routines, such as morning canoe paddling, to reinforce more explicitly that the Dene culture and way of life are inherently active. The organization has also been involving

parents in coaching, and the youth in forming sports teams to prepare for larger tournaments. Ultimately, the research generated conversations about healthy living in the community and reminded people that health and wellness are a collective rather than individual responsibility, providing an important foundation for future activities.

To fully achieve actions resulting from the research in the long term, strong multi-sectoral partnerships, dedicated programming, and evaluation could support the community to share resources, implement lessons learned, and translate knowledge into sustainable programs. Additionally, these efforts could address underlying factors such as culture and community development that are outside the health sector. Such a large-scale initiative could qualify as a population health intervention with the potential to shift the health and wellness outcomes of this community (Hawe & Potvin, 2009). In continuing the conversation, the community, researchers, and other partners are currently collaborating to determine health priorities that are relevant and meaningful to the community. Like this project, these conversations aim to build on youth as a community strength and agents of health promotion.

Linking Physical Activity with Culture, Tradition, and Land

The theme of cultural identity underpinned this entire research project. The subthemes were in fact values grounded in the Dene Laws, which are teachings regarded widely in the Dene Nation of the NWT as helping to guide people's lives through values in family, community, and traditional culture (Aurora College, n.d.). Two of the laws—"Be respectful of elders and everything around" and "Pass on the teachings"—directly reflect two subthemes discussed by the participants. Several other laws stipulate collective well-being: "Share what you have," "Help each other," and "Love each other as much as possible" (Blondin, n.d.). These teachings convey interconnectedness among community members and a sense of inclusiveness, which was another important subtheme from the analysis. These Dene Laws are prominent and pervasive in people's daily lives and explain why tradition and culture, and the link with traditional physical activity, are so important in this community.

Thus, Dene Laws reflect Indigenous knowledge relevant for the YK Dene people. As Kovach (2010) suggested, "[Indigenous] knowledges are bound to place" (p. 37). The significance of place and territory, land in particular, consistently surfaced during discussions of traditional way of life and cultural camps. Even Dene games were "heavily influenced by the connection between travel and life on the land" (Giles, 2005, p. 2). Many participants found solace in places such as the land where the cultural camp took place, which promoted physical activity and brought people together. Findings from this research supported the important relationship between land and Indigenous people's overall health and wellness.

A broader implication emerging from this research is the importance of land as a place for cultural connection, especially for the youth. This research illustrates a way to reconnect youth to their traditional culture while promoting community health and wellness. One avenue for future research is to focus on the relationship between Indigenous ownership of land and people's health and wellness. It would be instructive to investigate questions such as "How do land ownership and land titles matter in the health and well-being of Indigenous people? What is

the health impact of treaty negotiation processes and land claim agreements as perceived by community members?" By elucidating Indigenous experiences and perspectives, such research can greatly benefit the communication and relationship building between communities and government agencies engaged in negotiation and help them move towards common ground and reconciliation.

Limitations

We encountered challenges in video technicalities, scope of the footage, and the overall scope of the project. First, we faced technical difficulties with video production and iterative data analysis in the field. The researcher capacity in the field limited participant retention and engagement. Second, we wondered about the authenticity of the video footage. Despite our best efforts, it was not possible to comprehensively portray the total realities of the community. The sheer scope of filming during summertime excluded much footage from being incorporated into the final, publishable forms. Moreover, the videos that the youth made were very positive because they were contextualized within the strengths-based approach of the project. However, this approach may inadvertently skew the picture of people's lived experiences. To overcome this limitation of scope, we supplemented the videos with stories and narratives, for example, about winter activities, volleyball nights, and community drum dances. Finally, the scope of this short-term PAR project limited long-term evaluation of the actions that the community prioritized.

Conclusion

Through collaboration, we generated different meanings of physical activity to encompass understandings beyond "moderate to vigorous exercise regimes." We concluded that physical activity is cultural activity, and cultural promotion is health promotion, all grounded within Dene culture, tradition, land, and wellness. The process helped the community to reflect on the past and future, identifying ways to encourage people to be physically and culturally active not only through sports and exercise, but also through community involvement and a deeper connection with the land.

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Gimiigiwemin: Putting Knowledge Translation Into Practice With Anishinaabe Communities

Abstract

In the Anishinaabemowen language, *Gimiigiwemin* is a concept that means, “we are exchanging gifts.” In the context of research, Indigenous communities often share their gifts with researchers by exposing them to local ways of knowing. Researchers can engage in exchanging gifts through sharing their skills and working towards producing research that meets community needs, such as supporting efforts to maintain health-sustaining relationships with traditional lands.

Environmental repossession refers to the social, cultural, and political processes through which Indigenous Peoples are building resilience and reclaiming their traditional lands and ways of life. These processes are important because the health, ways of living, and knowledge systems of Indigenous Peoples all depend on access to traditional lands. This paper presents the results of a community-based participatory research study conducted in collaboration with Elders ($n = 46$) from two Anishinaabe communities on the north shore of Lake Superior (Ontario, Canada). This research employed locally relevant forms of integrated knowledge translation as a means of exchanging the gift of knowledge amongst all involved. This process culminated in a 2-day celebration wherein talking circles were used to explore Elders’ ideas about potential strategies for environmental repossession in their communities. Results from the talking circles pointed to four main strategies: (1) re-establishing the relationship between Elders and youth, (2) increasing time spent on traditional lands, (3) improving physical health, and (4) fostering community pride. This research emphasizes the strength of adopting culturally appropriate approaches to knowledge translation within studies aimed at supporting community aspirations of environmental repossession.

Keywords

Knowledge translation, Anishinaabe, Ojibway, Elders, Lake Superior, environmental repossession, community-based research, resistance, talking circles, qualitative

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Introduction

Indigenous Peoples globally continue to actively resist the effects of colonization, including devastating effects on community health. For instance, the physical and mental impacts of the residential school system in Canada continue to manifest across multiple generations (Kirmayer, Simpson, & Cargo, 2003). Resistance to colonization includes persevering in struggles to maintain access to traditional lands and the multiple benefits that result from this relationship to the land (Brown & Strega, 2005; LaDuke, 1999, 2005). Throughout Canada there are ongoing Indigenous struggles for recognition of legal land and resource rights, as exemplified by the circumstances motivating the Ipperwash dispute in the province of Ontario (Borrows, 2005). These efforts are occurring both within communities as well as on international stages, illustrated by the global reach of the Idle No More movement as well as support given to those resisting the construction of a telescope on the sacred lands of Mauna Kea in Hawaii (Cooper, 2012; Kino-nda-niimi Collective, 2014). Increasingly, academics from multiple disciplines have begun to ally themselves with Indigenous Peoples and are seeking to produce research that contributes to Indigenous resistance (Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011; Louis, 2007; Louis & Grossman, 2009).

Recently, Big-Canoe and Richmond (2014) introduced environmental repossession as a theoretical construct for exploring the social, cultural, and political processes by which Indigenous Peoples and communities are reclaiming their traditional lands and ways of life. The underlying assumption of this concept is that the uptake and practice of these processes may yield improvements in the health and well-being of Indigenous communities, as they foster opportunities for both improved social relationships and the practice of Indigenous knowledge. The concept itself emerged from qualitative research conducted in collaboration with Anishinaabe youth from the community of Biigtigong Nishnaabeg, which is located on the North Shore of Lake Superior. With an objective of better understanding youth perceptions about community health, the interviews revealed significant concerns among youth about the impact of decreased access to traditional lands on community health. The pathways through which disconnection from land impacts the health and well-being of affected Indigenous communities are varied. For instance, the 2008/10 First Nations Regional Health Survey linked increasing rates of both obesity and diabetes to decreased opportunities for physical activity and to the consumption of a less nutritious diet (First Nations Information Governance Centre, 2012). Conversely, spending time on the land provides the opportunity for meeting both of these health-sustaining needs.

Globally, in the rural and remote Indigenous context, there is a health-protective relationship associated with the land (King, Smith, & Gracey, 2009; Kingsley, Townsend, Philips, & Aldous, 2009; Richmond, Elliott, Matthews, & Elliott, 2005). Processes that strengthen the relationship between communities and their traditional lands, such as improving access to traditional land-based activities, lead to the adoption of healthy lifestyles (Isaak & Marchessault, 2008). For instance, Kirmayer, Brass, and Tait (2000) found that spending more time on the land in the company of other members of the community was associated with less psychological distress amongst the Cree of James Bay. In another study, Kingsley et al. (2009) found that more time on the land resulted in several health benefits, including building self-esteem, promoting a deeper sense of self-identity and value, enabling relaxation, and promoting cultural awareness.

This paper is the result of a larger study funded by the Canadian Institutes of Health Research (CIHR) and conducted in collaboration with two First Nations on the North Shore of Lake Superior: Biigtigong Nishnaabeg and the Batchewana First Nation of Ojibways. Chantelle Richmond is an Anishinaabe scholar from Biigtigong Nishnaabeg. Joshua Tobias is a non-Indigenous trainee completing his PhD with Chantelle Richmond within the Indigenous Health Lab at Western University. As such we were able to work within Dr. Richmond's existing social and familial ties within the community and the region, while still being aware of the need to foster new connections. In developing relationships, we strove to create an awareness of who we are as people and as researchers, in hopes that all would feel welcome and willing to contribute towards the research project.

The overall purpose of our research emerged from the need to preserve community Elders' knowledge about the relationships between health and traditional lands, as well as to develop strategies that could support the community's environmental repossession efforts. The project also sought to provide multiple sites of knowledge exchange between Elders, youth, investigators, and graduate students. As such, a research project was developed with a community-based participatory research (CBPR) approach that privileged both Indigenous and non-Indigenous ways of knowing and allowed researchers and the communities to work together as partners in creating and implementing the research. The hybrid approach taken within this research—through project development, recruitment of Elders, research implementation, and analysis—is detailed in a previous publication (see Tobias, Richmond, & Luginaah, 2013). The purpose of this paper is to explore how integrated knowledge translation was used to build strategies of environmental repossession.

Methods

Integrating Knowledge Translation

Recognizing a need to translate the knowledge gained through health research into applications that improve the health of Canadians, CIHR put forward calls for research that included a focus on the utilization of the knowledge gained to positively influence health. CIHR

defines knowledge translation as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (CIHR, 2016, section 2). CIHR goes on to state that knowledge translation occurs within a system of complex interactions between researchers and knowledge users that link academic health science research and improved health outcomes and programming. Knowledge translation is often categorized in two different ways: end-of-grant knowledge translation and integrated knowledge translation. Integrated knowledge translation entails the engagement with potential knowledge users throughout the entire research process (Graham et al., 2006). In a similar spirit to community-based research, integrated knowledge translation strives to prioritize the inclusivity and equality of all parties within research aimed at influencing health. It was precisely the process of engaged research that drew us to take up this framework in the first place.

Integrated knowledge translation has been framed as an important methodological approach within Indigenous health research because of its ability to act as an interface between two distinct ways of knowing that often seem in opposition (Estey, Kmetz, & Reading, 2008; Sherwood & Edwards, 2006; Smylie et al., 2009; Smylie et al., 2004). Within many Western knowledge systems, individual data are organized into abstract theory and require specialized training (i.e., advanced degree) to be fully understood (Brant Castellano, 2004; Little Bear, 2000). Typically, the objective of research conducted from Western ways of knowing rests on proving or disproving theory in attempts to enrich and advance the current knowledge on a particular topic. On the other hand, Indigenous knowledge systems are typically described as holistic and nonlinear. Knowledge is acquired through experience, is transmitted orally, is seldom sought without an applied purpose, and may even be framed as a gift (Battiste & Henderson, 2000; Kovach, 2009; Wilson, 2008). By emphasizing the use of culturally appropriate research methods, integrated knowledge translation provides the opportunity for Western and Indigenous ways of knowing to come together in order to create new knowledge that satisfies both approaches. Furthermore, integrated knowledge translation is a transformative method that nurtures the emergence of research environments wherein all collaborators can benefit from the experience of applying research in ways with which they may have had little experience.

Celebrating Our Research

Knowledge translation occurred throughout the research project (see Tobias et al. 2013, Tobias & Richmond 2014), from the collaborative development of our analytical framework to sessions for reviewing and providing feedback on preliminary results. Members of the research team were in contact with Elders, youth, advisory committee members, and members from each community throughout analysis of the research findings. Knowledge translation culminated in a 2-day Elders' Celebration held within each community (see Figure 1). The purpose was to relay the results of the initial in-depth interviews, provide space for reflection upon the results, and brainstorm strategies of environmental repossession. These celebrations were held approximately one year after initial in-depth interviews were conducted. All Elders who participated in the

initial in-depth interviews were asked to attend the Elders’ Celebrations. Invitations were also extended to other Elders who had not participated in the initial interviews and to spouses of those who were interviewed. Formal invitations along with transcripts of their initial interviews were delivered to the Elders approximately one month before the celebrations occurred. At this time Elders were also provided with an overview of the research findings to date. This allowed for private processing of the information prior to group discussion. Subsequently, members of the research team telephoned each Elder approximately one week before each celebration. Elders were informed about what was to occur at the celebration and were offered transportation and accommodations if needed.

Phase 1: Establishing Partnership	<ul style="list-style-type: none"> • Community meetings with Elders • Collaborative problem identification • Research agreements • Research strategy
Phase 2: Trainee Development	<ul style="list-style-type: none"> • Recruitment of youth research assistants • Graduate students introduced to the community • Training of youth and graduate students • Interview guide developed and practiced
Phase 3: Data Collection	<ul style="list-style-type: none"> • List of potential Elders created • Visits with Elders to explain research and offer tobacco • Interviews conducted
Phase 4: Data Analysis	<ul style="list-style-type: none"> • Analytical framework developed collaboratively • Interviews transcribed and returned to Elders • Iterative data analysis process
Phase 5: Elders’ Celebrations	<ul style="list-style-type: none"> • Ceremony • Presentations of research findings • Talking circles and focus groups • Feast
Phase 6: Action	<ul style="list-style-type: none"> • Communities implement action towards environmental repossession based on research results and celebrations

Figure 1. Phases of integrated knowledge translation.

The first day of the Elders’ Celebrations included an opening ceremony and introductions. An opening prayer was offered by one of the Elders, followed by a smudging ceremony. Upon completion of the smudging ceremony, a talking circle was conducted in order to introduce each of the individuals in attendance. Within the introductions, members of the research team discussed their roles within the project as well as their incentive for conducting the research. Several Elders took the opportunity to do their introduction in both English and Anishinaabemowin.

Prior to the Elders’ Celebrations, a discussion focusing on appropriate methods to obtain feedback had been held that included members of the advisory committee from each community as well as Elders. Together, it was decided that talking circles would be an appropriate way for

participants to share their views on the research findings as well as their strategies for implementing these findings in their communities. At the celebrations, an Elder who was familiar with talking circles was asked to explain the process so that all present had a common understanding. Although Indigenous communities have used them for many generations, it is only recently that talking circles have been increasingly incorporated within collaborative research (Hartmann, Wendt, Saftner, Marcus, & Momper, 2014). The talking circle has traditionally been used to solve problems or discuss important issues within communities (Wilbur, Wilbur, Garrett, & Yuhas, 2001; Wilson, 2008). Generally, those in attendance sit in a circle and a sacred item (e.g., eagle feather, grandfather stone, talking stick) is passed clockwise around the circle. This token signifies whose turn it is to speak, with others required to respectfully listen until the sacred item is in their possession. Individuals begin by introducing themselves and are encouraged to speak to the circle, avoiding focusing on any particular individual and confrontational dialogue. In similar fashion to focus groups, talking circles are a culturally appropriate means of determining where consensus and convergence surrounding a particular topic exists within a group. Momper, Delva, and Reed (2011) discuss how talking circles are an appropriate method within the context of collaborative research with Indigenous communities, as they act to remove the researcher from their traditional position of power and instead place them as equal contributors within the process.

Within talking circles, each individual has the opportunity to discuss what he or she may feel about a certain topic without interruption. A significant degree of openness and respect is shown to each of the individual opinions presented, thereby encouraging reflection and discussion (Kovach, 2009). Once every person has taken the time they need to express their individual opinion, at least one more round is conducted. On subsequent rounds, individuals can further express what they may have missed on the first round or can choose to react to what others have said. However, it is important to note that protocol exists when reacting to statements made by another person. For instance, it is rare that an individual would single someone out or directly dispute an opinion expressed by another participant. Instead, what often occurs is that individuals will express counter opinions without directly addressing the person with whom they disagree. Talking circles fit well within our application of the integrated knowledge translation method as it encouraged various types of knowledge to be shared, discussed, and recognized.

After the introductory talking circle, members of the research team led presentations detailing the overall findings of the in-depth interviews. While the themes presented were derived from data collected in both communities, each presentation was tailored to the respective community. It included an overview of expressed health and environmental concerns in each community, as well as a summary of the stated visions for the future of their community that each Elder was asked to provide at the end of their interview. This was followed by a screening of the film *Gifts from the Elders*, which was based on the knowledge collected in the Elders' interviews (<http://www.giftsfromtheelders.ca>). Once these presentations were completed, a catered lunch was served and the first day of the Elders' Celebration was concluded.

While the goals of the first day of the Elders' Celebrations were to share knowledge and discuss the importance of the findings, the key objective of the second day was to draw from focus groups and talking circles to build on the findings shared in Day 1 to develop action strategies. Focus groups consisted of four to six individuals with a member of the research team acting to transcribe for each of the groups using chart paper. Discussion was guided broadly by two questions. Participants were asked to provide feedback on the presentations and film screening, including any areas they would like explored further. We also asked participants to discuss strategies for implementing environmental repossession based upon the results that had been presented.

Each group was given the time that they required to address the specific objective. Focus groups concluded only when all groups believed that they had fully addressed the objective in question. Subsequently, an individual from each of the groups was selected to present their findings to all those gathered before regrouping in order to address the second objective. Once all groups had finished their discussion of the second objective, individual group members once again presented their findings. Overall, there was very little disagreement amongst those in attendance. The majority of participants typically agreed with strategies presented by others and were quick to add their own views to these propositions. We noted only one area of disagreement, which concerned the impacts of a proposed natural resource development project. However, this debate was expressed between two Elders who agreed that it did not merit significant attention within the context of our research.

Once talking circles and focus groups were completed on the second day, all those in attendance were invited to feast the conclusion of the celebration. Local caterers prepared the food for the feast and an Elder was asked to perform a prayer prior to the meal. The feast was appreciated as a way of wrapping up the events of the previous days with several laughs being shared amongst all in attendance. In Batchewana, the closing feast also included musical performances by Elders.

Analysis

The notes collected within each focus group form the data presented in the following section. Notes were transcribed and analyzed using QSR International NVivo 9 qualitative data analysis software. Data were analyzed thematically by creating nodes and sub-nodes for each suggested repossession strategy and then adding all data from across each focus group to the particular node. Coding queries were then conducted and explored to provide evidence for the importance of each node.

Results

The 2-day Elders' Celebrations resulted in the emergence of four themes that Elders in both communities described as key in their goals of environmental repossession: (1) strengthening relationships between youth and Elders, (2) increasing time spent out on the land, (3) promoting physical health, and (4) fostering community pride (Table 1). The following

sections elaborate upon each of these four themes.

Table 1
Key Findings From Talking Circles and Focus Groups

Theme	Challenge	Strategy	Outcome
1. Youth–Elder relationships	Youth spending less time learning from Elders	Elder–youth mentorship program, Christmas concert, use of social media	Re-establishing the role of Elders
2. Increasing time spent on the land	Need to strengthen relationship with traditional lands	Youth camps, ceremonies on the land, blueberry picking, seasonal workshops	Increasing opportunities for land-based youth–Elder social relationships
3. Improving physical health	Burden of diabetes and obesity acting as a barrier to well-being	Healthy eating workshops, community exercise programs, community gardens, Medicine Wheel workshops	Develop culturally appropriate and community-driven strategies to improve health and healing
4. Fostering community pride	Loss of Anishinaabe identity	Recognizing community role models, increased opportunities to practise Ojibway language	Reinforce positive identity as Anishinaabe people

Strengthening Social Relationships Between Youth and Elders

A key theme within the initial in-depth interviews was that the relationship between youth and Elders in both communities was at risk. Elders worried that youth were spending significantly less time learning from their Elders because of external demands placed upon them, such as the need to find employment and education outside of the community, as well as the large influence of technology (e.g., television, Internet, social media) in their everyday lives. During the Elders’ Celebrations, participants were keen to suggest strategies that they believed would strengthen their ability to connect with youth in their community.

First, there was consensus regarding the need to reinforce the traditional role of an Elder. To do so, the Elders stated that it was necessary to begin by creating the physical, social, and cultural spaces for these youth–Elder connections to occur. Elders described several locations that could be used by Elders and youth, including their homes, the community centres, and out on the land. Elders could take youth out on the land at various times throughout the year and provide activity-based learning to groups of youth, such as sharing traditional teachings around harvesting food and medicines.

Second, Elders were emphatic that the fostering of these social connections should be developed around the idea that both youth and Elders have important information to share with

one another. For example, Elders acknowledged that there was a great deal that they could learn from the youth, such as using computers and social media. Elders also stressed the importance of using an intergenerational approach to this learning, for example by including parents in developing and implementing Elder and youth activities.

Elders in both communities recognized the important potential of social media for being inclusive in their efforts. They discussed using Facebook as a means of spreading the word about activities. The fact that most individuals in both communities, Elders and youth alike, had access to this social network was seen as an opportunity for creating awareness of upcoming activities and sharing potential ideas for future plans. However, Elders cautioned against using social media to share knowledge. They strongly believed that being out on the land would always be the best place to share traditional knowledge with youth.

Finally, developing an Elder and youth buddy system was believed to be a positive way forward for increasing the role of Elders as youth mentors. This would involve pairing each participating youth with an Elder and having youth visit their Elder once a week. Elders suggested this would be the best opportunity for them to learn from youth, including having youth show them how to use computers and other technology. In exchange, Elders could share stories and teach youth about traditional activities such as beading or making moccasins and snowshoes. It was also believed that pairing Elders and youth could lead to an increase in participation from across the community. Perhaps most important, Elders again stressed the need to use a cooperative approach in creating these spaces; they suggested that the type of activity used to reinforce social relationships mattered less than the ways youth were empowered and made to feel important by being included in the decision-making process.

Increasing Time Spent on the Land

The importance of “getting back to the land” was discussed at length in the Elders’ interviews. In discussing their visions for the future of their respective communities, Elders from both Biigtigong Nishnaabeg and Batchewana First Nation expressed a strong desire to continue to nurture connection to their traditional territories, the main goal being to foster the practice, uptake, and preservation of their traditional Anishinaabe teachings and knowledge.

Elders identified time spent on the land as critically important for the preservation of Indigenous knowledge at the community level. Bridging with the previous theme, Elders agreed that many of the land-based initiatives could and should be aimed at increasing the connection between Elders and youth. Youth camps were identified as an excellent opportunity for youth to gain an appreciation for the cultural ties with their traditional territories. During the time when the initial in-depth interviews were being conducted, a 10-day youth camp was taking place involving high school students from Biigtigong Nishnaabeg. Time at the camp consisted of traditional teachings, bush skills, and team building exercises. Youth slept at Dead Horse Camp and did not have access to electronic devices. Elders were adamant that these youth camps should continue and were keen to be more involved in the camps in the future. It was proposed that workshops could draw upon the Indigenous knowledge and skills possessed by the Elders, such as trapping, hunting, medicine use, safety in the bush, and cleaning meat.

Conducting traditional ceremonies on the land also emerged as an important strategy for environmental repossession. While many of the Elders stated that they often conducted ceremony at their own homes, they identified the importance of doing ceremony openly out on the land. Several Elders emphasized the importance of this and reflected on how previous generations had often been forced to keep ceremony hidden. Two particular ceremonies were mentioned as being especially important in connecting with the land: the full moon ceremony and the sweat lodge.

In discussing the importance of spending more time on the land, annual blueberry picking was put forward by Elders in Biigtigong Nishnaabeg as an activity that everyone could participate in. This activity, although still practised by several members of the community, was seen as having changed significantly over time. Elders stated that they would like to see blueberry picking practised as more of a collaborative community event as opposed to an individual or small family event. This included distributing blueberries amongst families that were not able to collect, as well as sharing foods produced with the blueberries that were picked.

Bushwalks were discussed as an opportunity both to spend time on the land as well as to teach about the various ways that the Anishinaabe people are connected to it. Elders believed they would be able to share knowledge about local plants and animals. This included teaching the Ojibway names for local species, as well as teaching about how each could be used in medicines or for survival. It was also put forward that offering tobacco before a bushwalk, as well as before any other activities, was an important custom to follow as a way of showing respect to the land. Tobacco is one of the four sacred plants of the Anishinaabe people and is traditionally used to show respect and give thanks for the blessing bestowed by the Creator (Benton-Banai, 1988).

All of the above initiatives stress the important role that the land plays among First Nation communities. Increasing a sense of respect and responsibility for the land amongst residents, especially upcoming and future generations, was argued as being crucial for each community in their challenges of maintaining jurisdiction over their territories. Natural resource extraction along the North Shore of Lake Superior is increasing at unprecedented levels. This is often occurring without proper consultation and resulting in environmental contamination. Elders in both Biigtigong Nishnaabeg and Batchewana First Nation had previously encountered struggles to protect their natural resources and hoped that these would not recur in the future. Consequently, spending more time on the land would increase community knowledge of its jurisdiction and allow for prioritizing of full community participation in future resource development planning.

Promoting Physical Health

The third theme that Elders stressed was the promotion of physical health in their communities. During the initial interviews, Elders expressed great worry about the increase in health problems in their communities, including addiction, cancer, obesity, and diabetes. There were concerns that these issues would continue to affect future generations. Increased promotion of healthy eating habits and exercise was recognized as one key strategy for improving physical

health. Several Elders concluded that they would have to set examples of these behaviours themselves. However, they also indicated that such behavioural change required the creation of programming and activities. For example, ongoing initiatives such as group fitness and yoga were spoken of in high regard, and participants argued that these should occur with even greater frequency. Other suggested ideas for health promotion included group cooking and nutrition classes as well as an online forum for sharing healthy recipes.

Building upon existing community garden projects was also discussed as a way of improving physical health. While gardens existed in each of the communities, Elders were eager to see these projects expanded upon, and resources put in place to ensure their continuation year to year. Gardens were described as an essential opportunity for sharing Indigenous knowledge. One focus group suggested that youth tending to the gardens should be encouraged to fill baskets with produce and deliver them to the homes of Elders. They believed that this would instill in the youth a greater sense of ownership and pride over the garden project.

Related to nutrition and healthy eating, Elders also saw an opportunity for improving physical health by increasing interest in hunting, fishing, and trapping. They believed that all community members should be concerned with monitoring the quality of game and fish. Fond memories were shared of a time when the entire community participated in moose hunting, with meat being distributed community wide. There was a strong desire to see this practice re-introduced into the communities.

The need for a holistic approach to improving physical health in the communities was also discussed. The importance of Western medicine was recognized, as well as the need for regular visits with medical practitioners. The Elders attending the celebrations believed that further integration of modern and traditional approaches would yield greater improvements in health. Suggestions included hikes that incorporated traditional teachings and the development of a Medicine Wheel workshop. The teachings of the Medicine Wheel include a cultural framework for balancing physical, emotional, spiritual, and mental health (Isaak & Marchessault, 2008). Elders wanted their Medicine Wheel workshop to be guided by an Ojibway Elder from outside their communities and wanted the workshop to be open to all ages.

Fostering Community Pride

The final theme that was discussed at the Elders' Celebrations was the importance of fostering community pride. Elders were proud of their communities as well as their Anishinaabe culture. They stressed that it was important for all members of the community to have an increased sense of pride in who they are collectively as Anishinaabe people. They believed that being proud to be Anishinaabe was an essential means of preserving culture and traditional ways, including the protection of traditional territories. Several ideas were shared relating to ways that community pride could be nurtured.

Increasing the use of the Ojibway language was the most heavily discussed topic within this theme. Elders emphasized the importance of teaching the language to the youth at a very young age. However, they also stated that it was important for parents to be involved in the process and recognized that it would be difficult for older individuals to begin learning the

language. As such, many Elders put forward ideas geared towards active learning as a means of increasing the use of the language amongst all community members.

Elders believed that active learning of the language should include opportunities for talking to the youth in the language, such as during visits with grandchildren or designated times at the local daycare. Holding community language nights was also suggested. This would involve speaking the language at events such as bingo or community meetings. Another suggestion was introducing a number of labels around the community and at camps on the land. Labelling buildings and trees as well as placing posters around the community illustrating body parts or actions was also suggested as a good way to start. Teaching through stories, dancing, and song was another means of communicating in the language that Elders believed would be successful. Several Elders also expressed an interest in developing ways to integrate youth participation at community language events or in the youth and Elder pairing initiative within elementary and high school curricula.

An important suggestion discussed in both communities was the need to recognize and promote role models. This was discussed as being especially important as a means of getting youth interested in culture and being on the land. However, Elders discussed the need to identify these individuals, as many could name only a handful that they believed would be suitable. It was decided that these individuals should demonstrate a positive and clean lifestyle as well as maintaining a strong Anishinaabe identity. Elders were not opposed to including people from outside of their communities, but were especially keen on identifying those from within their own communities. Elders also discussed the importance of recognizing the Elders themselves as potential examples. Many were eager to put forward their stories of overcoming difficulties such as substance abuse in order to provide positive examples to future generations. The Elders suggested that an Elder recognition program was also very important. Several individuals in the community, many of whom were perceived by younger generations as Elders, did not see themselves as having yet attained this status.

Discussion

Drawing from focus groups and sharing circles, this paper shares the results of 2-day Elders' Celebrations wherein the identification of strategies for environmental repossession was the main objective. Despite grave challenges for the maintenance of their Indigenous knowledge as a result of a long legacy of colonization and various processes of environmental dispossession, the results of this paper illustrate how Elders in two Anishinaabe communities maintain a clear vision for upholding strong connections with their traditional lands, and they identify several strategies for realizing this vision.

Within the 2-day Elders' Celebrations, participants were eager to share what they believed were best strategies for practicing environmental repossession, including reconnecting Elders and youth, spending increased time on the land, improving physical health, and fostering community pride. Overall, Elders believed that the initiatives discussed throughout the two days were a good start to generating action around the previously collected interview data. They

expressed confidence in their ability to take the first steps towards enacting these initiatives and were eager to do so. However, Elders also recognized that it would be crucial for the momentum generated throughout the celebrations to be maintained. Elders did not want to force their will on the communities. Instead, they believed it was important to frame their initiatives as suggestions. They believed that individuals, especially youth, would be more inclined to participate if they could be involved in creating attractive and exciting programs. Furthermore, they argued that sustaining these programs over time was important in order to gain increased participation.

Finally, at the conclusion of the celebrations Elders expressed hope that the work they had done, and were going to do, would inspire their communities. They were also hopeful that this research and its outcomes would inspire other communities to design and enact strategies of environmental repossession.

While the desire to spend increased time on the land may initially seem like the most direct strategy put forward by the Elders, all areas that were suggested can contribute to processes of reclaiming traditional lands and ways of life. The ability to reclaim traditional lands and ways of life depends upon a young generation that is aware and excited about doing so. Furthermore, this requires individuals to be balanced within all aspects of the Medicine Wheel, including physical health. This also requires a deep sense of community pride.

The most discussed of these four themes in both communities was the need to strengthen the relationship between Elders and youth. Increasing individualism and the movement towards urbanization have been cited as contributors to the weakening role of Elders in Indigenous communities (King et al., 2009), and these problems are expected to worsen in the future. The eagerness with which Elders discussed their desire to improve their relationships with youth demonstrates that the Elders in this study still cherished this traditional role. Similarly, Big-Canoe and Richmond (2014) revealed that youth from Biigtigong Nishnaabeg also recognized the importance of their Elders and expressed concern surrounding the loss of knowledge associated with their passing. This points to the need for initiatives aimed at preserving and protecting the vital knowledge held by Elders.

However, Elder voices are seldom heard within typical health research. As demonstrated by the results of this study, Elders hold important visions for the future of their communities, including clear strategies for improving health. This points to the need for a greater Elder voice within Indigenous health research. Yet doing so necessitates that researchers are respectful of the unique ways of knowing and sharing knowledge held by these individuals. The successful inclusion of Elders in this study was the result of the CBPR approach (Tobias et al., 2013), which facilitated the adoption of culturally appropriate research methods.

This study also contributes to an evolving discussion about knowledge translation with Indigenous communities. The findings of this study highlight the importance of seeking to understand and include local processes of knowledge creation, dissemination, and utilization as a prerequisite to designing and implementing knowledge translation (Smylie et al., 2009). Regrettably, a legacy of exploitive research and the overshadowing of Indigenous worldviews by Western research paradigms have resulted in a longstanding exclusion of Indigenous Peoples

from research that could contribute to improving their health status (Menzies, 2004; Smith, 1999). Integrated knowledge translation represents a promising pathway bridging this divide, including the production of research aimed at taking action on issues of importance to collaborating communities. However, to be successful within the context of Indigenous communities, the customary practice of integrated knowledge translation must draw upon the key values of CBPR (Lencucha, Kothari, & Hamel, 2010). This includes building partnerships with communities based upon respect and reciprocity at the onset of project development. Once these foundations have been created, effective and locally relevant strategies for implementing knowledge translation can be developed.

Future research exploring environmental repossession amongst Indigenous populations should continue to emphasize the underlying strengths-based approach that the concept of repossession puts forward. Doing so will contribute to further shifting the nature of Indigenous health research away from focusing on problems and towards the increased exploration of thriving health initiatives within the Indigenous context. Furthermore—as demonstrated within this paper—CBPR and knowledge translation facilitate the development and implementation of research projects that can yield data to support local health initiatives. Further research should strive to strengthen the case for adopting these approaches by exploring the merits and challenges of doing so from the perspective of community collaborators and participants. In such investigations, the academic research can become the researched.

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Towards an Aboriginal Knowledge Place: Cultural Practices as a Pathway to Wellness in the Context of a Tertiary Hospital

Abstract

The Indigenous community in Australia is beset by extraordinary disadvantage, with health outcomes that are substantially worse than those of non-Indigenous citizens. This issue has consequently been the subject of voluminous health research that has given rise to a range of affirmative action policies progressively implemented over the past decade. Statistics, however, remain dire. This paper argues that new models of research practice and policy are required that are inclusive of Indigenous ways of knowing, doing, and being. It proposes a new framework to promote wellness in urban hospitals for Aboriginal young people and their families modelled on equal, 2-way dialogue between Western and Indigenous ways of doing health. Cultural safety is an essential starting point, but a range of other practices is proposed including oversight by a board of Elders, inclusion of traditional healers in treatment teams, and “space, place, and base” within the hospital building and its grounds so that it can be used as a site for culturally engaged Indigenous outpatient care. Practice approaches that embed culture into assessment, formulation, and treatment are being trialled by the authors of this paper, three of whom have Aboriginal heritage. Together the authors are working toward building an Aboriginal Knowledge Place within the major teaching hospital where they work.

Keywords

Aboriginal people, Australia, health care, transcultural, place, nomothetic, ideographic, Indigenist

Glossary

Aunty and Uncle: titles of respect for women and men who are considered to carry significant knowledge and wisdom.

Country: tribal lands, inclusive of waterways, plants, animals, rocks, and celestial bodies. To be “on Country” or “off Country” indicates whether someone is physically present on or distant from their tribal lands.

Deep listening: quiet, contemplative, listening with a spiritual dimension.

Story: significant narrative emerging from an Indigenous ontology (Langton, 2002).

Welcome to Country: a ritual that is considered important for cultural safety within Aboriginal culture. It is offered by a “Traditional Owner” (someone with tribal connections to Country) to all visitors to protect them from the emplaced ancestral spirits who dwell in the land and waterways.

Yarning: a word that describes conversation that is inclusive of “deep listening.”

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Introduction

Despite a range of policies implemented to address Indigenous health disadvantage in Australia (Anderson et al., 2006), Indigenous health outcomes remain dire. This paper will argue that the policies are fundamentally limited because approaches emerge from Western epistemologies that are wholly different from Indigenous "ways of knowing, being, and doing" (Martin & Mirraboopa, 2003). Indigenism, a new field of research that has emerged over the past 10 to 15 years to critique the dominance of Western epistemologies within the academy, has recently been employed as a methodology within health research and regional, community-based health care, but has not yet filtered into policy and practices in mainstream city hospitals. Urban hospitals remain alienating and undesirable paths to wellness, but they are often unavoidable as they are the only place for treatment for many complex health challenges. The authors, three of

whom have Indigenous heritage, work within a child mental health service in the state of Victoria, Australia.

This paper will describe the process these authors are undertaking to develop a model for an Aboriginal Knowledge Place in which Indigenism is enlisted to holistically augment Western biopsychosocial treatments, especially when Western medicine alone has failed. Improving cultural safety is an essential starting point, but a range of other practices is proposed: transformations to spaces within the hospital building and grounds so that they can be used for culturally engaged Indigenous outpatient care; trial practice approaches that embed culture into assessment, formulation, and treatment; traditional healers in treatment teams; and increased social and political agency through supervision and oversight by a board of Elders. The paper contextualizes the concept with an overview of progress to date and concludes by suggesting how the outcomes of full implementation of such a model could inform broader changes within communities and the health system.

Background

Research Methodologies and Policies for Indigenous Health Care in Australia

Broadly speaking, the literature that has informed Indigenous health care policy documents can be readily classified using the nomothetic and ideographic framework that emerged from the personality research field in the 1950s (Beck, 1953). Nomothetic research examines phenomena that can be objectively defined using psychometrically valid and reliable measures. Diagnostic groups can be characterized by phenomena that are believed to be generalizable across social and cultural contexts. In contrast, ideographic research explores numina that have an inherent significance, force, and power, defined subjectively by individuals. These numinous aspects are considered unique for each individual as defined by and for themselves. Both nomothetic and ideographic approaches are considered essential for good clinical practice (Bloch, 1997). For instance, biopsychosocial risk and resilience factors arising from nomothetic inquiry may be informed by ideographically defined coping styles, belief systems, and illness and wellness behavioural styles. Together these types of knowledge affect understanding of diagnoses, clinical formulations, and treatment plans that in turn influence engagement and adherence to medication and/or psychosocial treatments prescribed and the subsequent health outcomes achieved.

To date, the majority of research focused on Indigenous health in Australia has been nomothetic with some illustrative ideographic case histories/case examples to emphasize key themes. They include quantitative research targeting demographic risk factors (Australian Bureau of Statistics, 2010) and environmental risk factors (Clough et al., 2004; Dingwall & Cairney, 2011; Gault, Krupinski, & Stoller, 1970; Lee et al., 2009; McKendrick et al., 1990) as well as qualitative research focused on social risk factors (Bostock, 1924; Cawte, 1963, 1988; Eley et al., 2007; Hunter, 1991; Petchkovsky & San Roque, 2002) and clinical practice (Hunter, 1993, 2004; Peeters & Kelly, 1999; Turale, 1994; Ypinazar, Margolis, Haswell-Elkins, & Tsey,

2007). These studies have in turn informed important policy documents that have sought to frame a national response to the plight of Australia's First Peoples across health, education, and welfare sectors (Baxendell, 1997; Council of Australian Governments, 2008; Dudgeon, Milroy, & Walker, 2014; Dwyer et al., 2011; Eckermann, Dowd, & Chong, 2006; Edwards & Madden, 2001; Human Rights and Equal Opportunity Commission, 1997; Swan & Raphael, 1995).

The national apology to Aboriginal and Torres Strait Islander people (Australian Government, 2008) provided impetus and direction for a politically bipartisan, national and state government initiative termed "Closing the Gap in Indigenous Disadvantage." Key aims were to increase life expectancy, decrease child mortality, and improve educational and employment outcomes for Australian First Peoples. The National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes (Council of Australian Governments, 2008) outlined a program of reform focused on the first two aims with five broad priority areas identified. The *Close the Gap Progress and Priorities Report* (Holland, 2014) makes some compelling points about the work done to date. Specifically, it outlines the importance of developing a dedicated mental health plan and alcohol and other drug strategy for Aboriginal and Torres Strait Islander Peoples. It also emphasizes the need for an integrated approach to health issues and their social and cultural determinants, including the impacts of intergenerational trauma. Further, it associates this broad and integrated health strategy with the future development of a Closing the Gap program to decrease rates of incarceration, crime victimization, and out-of-home care. In 2010, *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice* was published (Purdie, Dudgeon, & Walker, 2010), and is now in its second edition (Dudgeon et al., 2014), with funding from the 2006 Council of Australian Governments Mental Health Initiative.

All of these policy documents are based on quantitative research and have included extensive ideographic case history narratives to inform key action principles, targeted aims, and models for clinical practice. Each advocates for a holistic model of care, culturally appropriate therapies, and genuine dialogue and partnership between Indigenous and non-Indigenous systems of health care.

Although the ideographic is typically positioned as a culturally inclusive approach, we argue that both nomothetic *and* ideographic research emerge from within a contemporary Western academic paradigm that has arisen from the Enlightenment, a period in the 17th and 18th centuries when reason and analysis emerged as the dominant epistemologies (Bristow, 2011) and individualism framed its cultural mores (Habermas, 1989). The same forces drove global exploration and colonization of Indigenous cultures during that era. Nomothetic research places emphasis on reasoned, objective, quantitative method, while ideographic research emphasizes the individual experience. In contrast, Indigenous epistemologies and cultural mores arise from different forces altogether. Kinship systems and a concept of "reciprocal belonging" (McGaw & Pieris, 2015, pp. 73-74) to *Country* (see Glossary) situate the individual within a network of human, ancestral, geological, and totem relationships that this paper will argue are equally important to health. These values and beliefs are not quantifiable, not measurable, and

not individually defined.

New Modes of Research Emerging from the Indigenist Critique

A growing number of Indigenous academics around the world have begun to critically reappraise the Western framing of their research fields (Garrouette, 2005; Lavallée, 2009; Martin & Mirraboopa, 2003; Rigney, 1999; Smith, 1999; West, Stewart, Foster, & Usher, 2013; Wilson, 2009). The term *Indigenism* has been coined to describe such an approach, drawing associations with other critical, liberation epistemologies (for example, feminism, poststructuralism, post-colonialism). Indigenist research aims to critique the Western research paradigm and provide an alternative discourse that centralizes Indigenous ways of knowing and being. Indigenist research requires Indigenous people to conduct research according to the following principles, enunciated by Martin & Mirraboopa (2003): Each people's worldview is distinctive and vital for their existence and survival; each people's collective social mores must be honoured as essential processes through which they live, learn, and situate themselves; each people's contexts are acknowledged as key shapers of their interpretation of past, present, and future experiences; and each people's voice, experience, and life and their lands are privileged. As the great Lakota chief Ota Kte (Luther Standing Bear) wrote:

The spiritual health and existence of the Indian is maintained by story, magic, ritual, dance, symbolism, oratory (or council), design, handicraft and folk-story. To check or thwart this expression is to bring about spiritual decline (Standing Bear, 1933, p. 255).

Indigenist academics strive to add to the knowledge acquired via the Western research paradigm so that policy, practice, and evaluation may be more socially and culturally informed with respect to Indigenous Peoples. Rigney (1999) emphasises the need to liberate Australian Indigenous knowledge from the control, storage, and extraction techniques inherent in the Western academic discourse. Smith (1999) argues as a "colonised" Maori woman that Western research and knowledge paradigms need to be decolonised so that research can cease being "one of the dirtiest words in the Indigenous world's vocabulary" (p. 1). Garrouette (2005) calls for the Western academy to embrace an American Indian "radical Indigenism" that involves wholly new models of inquiry, especially the meaning and utility of the "subjective" and different constructs of the "observable" along with "unique (non-repeatable) events" (p. 170). Lavallée (2009) outlines how the epistemological and ontological basis of research affects a project, determining what is considered worthy of study, what and how research questions are asked, and what approach is taken to analysing and interpreting data. She asserts that Indigenist researchers should frame all these aspects of a project from the standpoint and foundation of their culture (Algonquin, Cree, and French Métis for Lavallée).

The philosophy of science has aided the development of the Indigenist discourse, establishing the epistemological and ontological basis for Indigenist research from which methodologies flow. However, the health field has been slower to embrace what are perceived to

be non-evidence-based approaches despite the obvious failures of Western lifestyles, medicine, and health care to deliver wellness to Aboriginal and Torres Strait Islanders in Australia. Cunningham and Stanley (2003) signalled the urgency of rethinking health from an Indigenous worldview, but to date relatively few research publications have done this. Exceptions include a posthumous Indigenist paper by Joe Roe (Purungu), a Karrajarrri/Yawru man on Ngarlu (a cultural and spiritual strengthening model; Purdie et al., 2010) and Hovey, Delormier, & McComber's (2014) research into diabetes prevention that argues for a social-relational perspective inclusive of a spiritual realm.

There is, however, an emerging practice-based literature that advocates for embedding Indigenous ways of knowing, doing, and being in primary health care delivered in communities and brokered by Aboriginal health care workers. Western models for health continue to drive care, but there are signs of greater equality in the two-way communication between Western and Indigenous paradigms. *Binan̄ Goonj: Bridging Cultures in Aboriginal Health* (Eckermann et al., 2006), following Kelly and Sewell (1991), argues that communities, rather than hospitals, are best positioned to create paths for wellness as they offer people space (geographic location), place (a space where identities and belonging are produced), and base (space and place where people have economic, social, and political agency). In addition, there have been a number of local affirmative health programs, led by Aboriginal people for Aboriginal people, that privilege local cultural knowledge and practices.

Community health models have their obvious advantages. They offer an approach in which power paradigms are inverted and Aboriginal epistemologies are normative. However, the majority of Aboriginal Australians live in major urban centres where health care for serious illnesses continues to be delivered in hospitals. As a consequence this paper suggests that a framework for decolonising health care within an urban hospital setting remains important. The recent study *Managing Two Worlds Together* (Dwyer et al., 2011) noted that 4% of all hospitalisations from 2013 to 2014 were Aboriginal or Torres Strait Islander people, although they make up only 2.5% of the national population. It further noted that while Indigenous adults are almost twice as likely as non-Indigenous adults to present to a city hospital, they are more than 6 times as likely to present to a country hospital. From these statistics it seems that city hospitals may be *both* an essential place for delivering health care for Indigenous populations, *and* an alienating and undesirable destination. Primary concerns of patients were about difficulties of organizing transport to and accommodation near hospitals, disconnection from family, worries about cultural aspects of care (especially dying off Country), and perceptions of systemic racism (Dwyer et al., 2011). Health care professionals' observations of the experiences of Indigenous patients and their families were similar, although they also identified concerns about compliance to clinical regimes, difficulties gaining consent for treatment, and the importance of Aboriginal health workers as advocates and cultural brokers, which they acknowledged is a broad, stressful, and burdensome role (Dwyer et al., 2011). Staff reported glimmers of accommodation to Indigenous ways of doing health, where occasionally traditional healers have performed smoking ceremonies to cleanse rooms and move spirits on as a way of

allaying fear and anxiety. But on the whole cultural practices were seen as secondary to Western models of care and ignored or excluded if there were perceived conflicts (Dwyer et al., 2011). Hovey et al. (2014) argue that in Canada, health care in hospitals is increasingly “culturally sensitive” but not yet “culturally safe,” as medicine continues to be filtered through a Western paradigm that perpetuates colonisation. In New Zealand, efforts to improve cultural safety have resisted cultural awareness education, out of concern regarding ossifying stereotypes, in favour of increasing opportunities for Maori people to lead health care programs (Ellison-Loschmann & Pearce, 2006). Unlike Canada and New Zealand, which signed at least some treaties with their First Peoples, Australia’s colonisation is marked by a process of unrivalled dislocation from land and dispossession of culture. A framework for hospital-based Indigenous health care must not only improve cultural awareness and increase the representation of Indigenous staff in delivering care (following Kelly & Sewell, 1991), it must develop new models for care and new ways of providing “space, place, and base” for Aboriginal people within urban hospitals.

A New Framework

Three of the authors of this paper are clinicians with Aboriginal heritage in a tertiary, hospital-based, treatment-nonresponsive developmental neuropsychiatry program (DNP) at the Royal Children’s Hospital (RCH) in Melbourne. This program works closely with the Aboriginal Liaison Unit, Wadja Aboriginal Family Place. At present, the authors are working to establish an Aboriginal Knowledge Place that augments Wadja Aboriginal Family Place. The following are the elements under consideration as they develop a new framework to bring Aboriginal ways of knowing, doing, and being into dialogue with Western medicine.

Space

In urban hospitals there is little spatial certainty for any patient who is shuffled variously between waiting rooms, outpatient clinics, emergency department trolleys, and inpatient beds. But for Aboriginal people the sense of disempowerment can be magnified by the cultural strangeness of Western medical care and geographic isolation from family and community. Most Australian hospitals have Aboriginal liaison units operated by social work departments to alleviate these anxieties. Wadja Aboriginal Family Place, for example, has a spatial presence within the institutional context of the hospital that Aboriginal people can use as a geographic safe haven. Outpatient clinics can be run from the centre and there is also a comfortable space where families can spend time with their “mob” and an outdoor area to escape from the confines of the hospital’s interior. But the centre is small and isolated in the hospital context and is not easily located by visitors. Maintaining and augmenting such a facility is an ongoing challenge in an increasingly stringent economic context. It is interesting to consider that hospitals generally are increasingly confining. Over the past 150 years, hospitals on average have decreased in ward space by 70% (Connellan et al., 2013).

The challenge of getting to hospitals is also often significant. Many hospitals are located in the heart of cities a long way from the peripheral suburbs where marginalized communities are

often found, and the journey to hospital takes time, organisation, and money. It requires either negotiating public transport (which can be challenging for people who are unwell) or driving and parking, which can be extremely expensive. Once patients leave hospital and make their journey back home, there are few reliable networks to ease the transition between hospital and communities and to support the path back to wellness.

The spatial challenge for urban hospitals is thus twofold: to provide spaces that are culturally safe havens within the hospital infrastructure, ideally including temporary accommodation of families who are supporting inpatients; and to develop better processes of connection with community-based care once patients are discharged.

Place

Aboriginal cultural identity formation is closely linked to space. As Kelly and Sewell (1991) argue, the spaces where identities and belonging are produced become “places.” Three Indigenous themes of place are particularly relevant for health: Country, totem, and *Story* (see Glossary). These are being incorporated, in genuine dialogue with Western health practice, into a novel clinical service in the DNP by three of the authors.

Country is central for Australian Aboriginal identity—not generalisable or abstract but specific, local, and immediate. Specific landforms and waterways convey evidence of the ongoing action of creator spirits (see McGaw & Pieris, 2014). The relationship between people and land is one of mutual belonging. Indigenous concepts of Country, which hold that respecting, maintaining, and caring for Country is paramount, are diametrically opposed to the Western paradigm of land as property (Cunningham & Stanley, 2003). Social responsibility to one’s kin is expressed through the rituals enacted in the sacred landscape, according to Langton (2005). Colonial laws have displaced Indigenous people from Country, and in turn separated people from their kin, totems, and sacred Stories. Indigenous dislocation was arguably greatest in the southeastern states of Victoria and Tasmania, although there were no parts of the continent that were left untouched.

Part of caring for Country involves caring for totem animals, trees, and plants. Totems are complex, multifaceted, and difficult to describe outside of Aboriginal culture. They are a primary means of responsibly caring for place, managing and balancing multiple ecological systems, and maintaining Story. The term *totem* originated from the Aboriginal Peoples of the United States and Canada and has become universally used by Western scholars to describe the ongoing system of spiritual and practical connection between Indigenous people and place, animals, and plants (Grieves, 2009). The totemic system arose from the ancestral law developed at the time of creation. It reinforces human beings and the natural world as one indivisible whole; the same matter but different form. Through ritual, ceremony, and customs Aboriginal people and their totems and ancestors become fused in a single reality. This fused reality is lived out through maintaining the relationship with the totem species, for example, and with the sacred sites where the totem is connected with the emplaced ancestral spirits. Although the majority of Victorian Aboriginal people were displaced from Country and cultural practices through the

colonial period, totemic ideas persist. In some instances they have been diluted to a concept of allegiance, not dissimilar to non-Aboriginal “tribal” allegiances such as supporting a football team, but for others, totems remain an organising principle for Aboriginal tribes, clans, and families and give rise to persistent customs, ceremonies, and rituals. These actively remember the achievements of the ancestral spirits and give the initiated identity, meaning, and purpose through ongoing connection with them. If one’s totem is an animal, you are responsible for nurturing and caring for that animal. One studies its appearance, behaviour, coping styles, movements, sounds, and living patterns and learns from it and emulates its feats. Through ceremony, custom, and ritual one adds to the life of the animal and so too is enhanced in return.

Story is another important means for connecting with and caring for Country and its emplaced ancestors. A marker of maturity in Aboriginal culture is to know one’s Story, enact it “on Country,” and upon one’s death become the totemic ancestral spirit and return to one’s Story place. Particularity is crucial. Specific people in specific places know specific parts of Story given to them because of who they are becoming within a family, clan, and tribal group. Story is independent of linear time. There is no past or future—just present ongoing Story. According to Watson (2009), English translations such as Dreaming and Dreamtime story do not capture the full meaning of Story. She notes that Western understandings of place as a commodity that can be bought and sold is at odds with the relational understanding of Country that underpins Indigenous place making. Stories recount the source of a person and their kin through their ancestors, and generally must be told in the location where the ancestors are emplaced forever. These sacred Stories remain inextricably linked with law and morality and govern interpersonal attitudes and behaviour. Exact repetition is of paramount importance; this practice has enabled Stories to be maintained faithfully for thousands of years. The carrier of a Story is accorded privileges, including rights to land connected with a Story and the right to decide when and to whom to hand on a Story. But there are also responsibilities. Strict rules must be followed about their transfer to others: to whom, and through what modes of practice. In Stories place is central to interpersonal ethics, law, and land rights. To be whole, the Aboriginal person must know his or her Story. Given the fragmentation of Indigenous culture through the era of colonisation in Victoria, many Stories are no longer maintained. The authors of this paper argue that this loss is a poorly understood factor contributing to the dire statistics on Indigenous health.

So how might Country, totem, and Story telling become part of a therapeutic relationship? Brearley and Hamm (2009) developed what they describe as a research methodology that sits between Indigenous and non-Indigenous knowledge systems. The methodology pairs story telling with responsive *deep listening* (see Glossary), which has its own word in many Aboriginal languages: *ngarrwa nyarrwa* in the Wurrung language of the first author. Deep listening begins with a commitment to respecting Indigenous knowledge systems as different yet equal. Intuition, spiritual experience, and unverifiable conversations can be central to communicating and understanding Indigenous knowledge. While these have a currency in psychodynamic traditions, they are often perceived as problematic in current multimodal evidence-based approaches. Brearley and Hamm (2009) argue that deep listening develops

through empathy and unfolds over time. While it is core to Indigenous ways of knowing and being, when practised by non-Indigenous people it offers a path toward reconciliation. Egyptian scholar Mehrez (1991) argues that it is only when colonisers situate themselves in the narrative of dispossession that the work of decolonisation can begin. Similarly, this paper argues that wellness models for health in Australia should include opportunities for Aboriginal people to move beyond the confines and interiority of hospital buildings to reconnect with Country. It also argues for the benefits of enlisting relational totems as an implicit part of the network of healing relationships for Aboriginal patients.

Base

As Kelly and Sewell (1991) write, spatial transformation and opportunities to form identity through embodied ritual practices on Country are not enough. Aboriginal people also need economic, social, and political agency within the places they inhabit. This is easier to achieve in community-based health programs than hospitals. Many patients, regardless of cultural background, feel disempowered within hospital settings, where illness rather than wellness predominates. However, there are some key steps that hospitals can take.

First, a co-leadership model for Aboriginal and non-Aboriginal ways of doing health is necessary so that genuine and meaningful dialogue can occur rather than merely helping Aboriginal people to better comply with non-Aboriginal health systems. Second, a governance group of Aboriginal Elders is crucial to provide (a) a culturally safe place for the above dialogue to occur, (b) cultural oversight and day-to-day supervision for the varied healing practices within Aboriginal culture, and (c) leadership in the political and economic processes of the hospital and health system at large. Traditional healers would ideally be part of this group. Finally, hospitals must provide ongoing cultural awareness and safety training for all staff in order to maintain genuine Aboriginal and non-Aboriginal dialogue.

Methods, Preliminary Results, and Discussion

Towards an Aboriginal Knowledge Place

Although there is no funding yet for full implementation of an Aboriginal Knowledge Place, important first steps have been taken, which will be described in more detail below. To summarise, the authors of this paper began a process of statewide consultation with leaders within the Aboriginal community in Victoria 18 months ago to seek their guidance and support for such a venture. The RCH has since engaged an external consultant to do a cultural safety audit and make recommendations. The authors of this paper who are involved in clinical care have ethics approval for this work as a clinical quality improvement initiative. So far 10 young people and their families have been managed in this new way. Initial results are very promising. Further formal qualitative and quantitative evaluations are planned once 50 or more cases have been managed through the program. These will be published in due course.

The first step has been to consult with Aboriginal leaders across the state of Victoria. So far a dozen key Aboriginal leaders have been involved. Unlike meetings within non-Indigenous organisations which are often organized by email, brokered in groups with organizational hierarchies, and carried out with a clear agenda and time keeping, this consultation has followed the model of community-based Indigenist health care in which Aboriginal ways of knowing, doing, and being are central. The process of consultation has been broad and inclusive. Aunties and Uncles from Melbourne and regional Victoria as well as directors of advocacy groups for Aboriginal health and welfare have been included in discussions. The latter are well positioned to advocate for and lead change within health, education, and welfare departments. The first author has personally met with them all—sometimes on Country, other times at Wadja Aboriginal Family Place and the gardens around the hospital or at their place of work. The meetings have allowed opportunities for yarning.

The model that has evolved through the consultation to date is for an Aboriginal Knowledge Place that can develop an alternative approach in which Indigenous ways of knowing and being are enlisted to augment Western biopsychosocial treatments, especially for treatment-nonresponsive cases. The existing culture, ethos, and clinical service delivery model of the Wadja Aboriginal Family Place is preserved and extended by the Aboriginal Knowledge Place in the following ways:

1. A co-directorship model involving Aboriginal and non-Aboriginal directors should be established, as in extant world-leading Indigenous cultural centres.
2. An advisory group of Victorian Traditional Owner Aboriginal Elders representing the North–South–East–West of Victoria should be convened to meet with the directors quarterly or more frequently as needed to deal with roadblocks to delivering health outcomes.
3. Aboriginal culture, especially Country, totem, and Story, should exist in genuine dialogue with Western health care models for Aboriginal young people seen at RCH.
4. Care arising from this holistic genuine dialogue needs to extend back into the communities where Aboriginal young people live, so that Aboriginal and non-Aboriginal models of health, education, welfare, and justice are advocated for and integrated.
5. It is hoped that teaching programs for Aboriginal and non-Aboriginal people will arise from this genuine dialogue and be made available for Aboriginal and non-Aboriginal health, education, welfare, and justice staff.
6. Research programs should use qualitative and quantitative measures to analyse outcomes from the Aboriginal Knowledge Place database, providing unique insights. Research insights would be fed back iteratively and seamlessly through the teaching and advocacy/integration practices. It is envisaged that such an Aboriginal Knowledge Place could nurture equity and innovative health care practice from which all can learn and benefit.

As with all ventures of this nature, resourcing is the most difficult hurdle to overcome. Formerly, the RCH and Aboriginal Hostels Limited jointly ran an accommodation for Aboriginal families across the road from the hospital at an Aboriginal hostel. It was considered a culturally safe place for families to stay while their children received treatment, but it was closed down for

reasons of funding. Employing a Woiwurrung Elder to welcome people to Country is also considered too costly. In light of this, the team has strengthened links between the DNP and community culture-based programs that already exist and achieve excellent outcomes in improving health. They are also encouraging the inclusion of cultural discussions and encounters with Indigenous patients and their families to facilitate a broader clinician–client engagement and deeper mutual trust that enables the journey to health.

The DNP is a tertiary referral outpatient clinic that is led by a psychiatrist (the first author) and clinical and educational psychologist (third author) who work closely with the head of Koori Mental Health (fourth author). It receives referrals from metropolitan and regional schools, primary health care teams, and secondary specialist services in the state of Victoria, Australia. It conducts a comprehensive assessment of cases using integrated information from detailed multi-informant clinical interviews and examination and standardized biopsychosocial measures. Treatments vary from case to case, but they often involve a 6-month synergistic systematic trial of first- to third-line medications to enhance engagement in individual and group cognitive behaviour therapy (CBT) programs involving parent and teacher management training. The clinic has treated over 1,000 cases over the past 5 years. Successful outcomes are achieved in 72% of referred cases, previously deemed treatment nonresponsive (for more details about the DNP, see http://www.rch.org.au/acpu/about_acpu/Developmental_Neuropsychiatry_Program/). In contrast, 31% of Aboriginal young people managed through the clinic had successful outcomes prior to commencing an “Indigenist dialogue” as part of care.

Under the new model, Indigenist dialogue, in which Indigenous ways of knowing and being are enlisted to augment Western biopsychosocial treatments, unfolds when opportunities arise. If a client reveals during assessment and/or treatment sessions that they are Indigenous, this is recognised and reinforced through the clinician synchronously sharing, mirroring, and reinforcing the importance of their own and the client’s Aboriginal heritage. The clinician is then able to draw parallels between Western health interventions and Aboriginal cultural ways of doing health and being healthy. Sometimes, care is delivered walking or sitting with a chaperone in the gardens, rather than in small windowless consulting rooms. Clinical quality improvement audit outcomes seem promising: 10 previously treatment-nonresponsive Aboriginal patients have made marked improvements. The young people and their families seem to develop a greater faith in the formulation and treatment planning processes to aid successful treatment outcomes. Furthermore, in more complex ways, engaging cultural knowledge and identity through Indigenous perspectives of place equally facilitates the journey to health. Each young person has become progressively more focused and centred, deeply aware of their rights inexorably linked with their responsibilities to Country, totem, and Story.

There is a clear advantage for the clinician to have Aboriginal heritage when engaging in such a dialogue. Furthermore, the availability of Aboriginal health workers to see cases alongside non-Aboriginal clinicians can be invaluable. Although, it remains a day-to-day dilemma that their numbers are too few in the health service system. Despite the particularity of Aboriginal cultural understandings of place, dialogue between Aboriginal people from different

language groups and cultural traditions is time honoured and expected. While Country, totem, and Story are important in the journey to health for some, others in the Aboriginal community might construct their social identity differently. Hence the importance of deep responsive listening as part of the clinician–patient dialogue.

A comprehensive evaluation is being developed to determine what parts of the new model of care work best and what aspects need to be reformulated. Qualitative information will be collected pre- and post-intervention by clinicians through interviews with each young person seen in the Aboriginal Knowledge Place program and the key family members involved in their care on a day-to-day basis. Community Elders will be invited to provide qualitative feedback and insights. They will be engaged in running and supervising cultural practices and aiding connections between the Aboriginal Knowledge Place work at the hospital and the community where each young person and family live. In addition, each clinical case manager and the senior managers of each involved service will be interviewed to add their views to all the qualitative information obtained. Similarly, quantitative data will be collected pre- and post-intervention about the Aboriginal Knowledge Place program by adding measures about health, education, and welfare outcomes to existing hospital and service measures already collected as part of the Victorian Government key performance indicators. Each young person, involved family members, clinical case manager, and senior service manager will complete this quantitative measure that has been formulated for their age and educational level. Together these data will enable us to work towards putting together a randomised controlled trial evaluation of the Aboriginal Knowledge Place.

Creating a cultural safe space is an essential starting point. The RCH has engaged a national Indigenist therapeutic organisation to work with its executive to improve cultural safety in the hospital. But a range of other practices has been proposed by Elders around the concept of the Aboriginal Knowledge Place. Initiatives already underway include formal referral pathways for ongoing care of Aboriginal young people served at the hospital with a community-based Aboriginal wellness and connection practice, Wayapa (<http://www.wayapawuurk.com>). In lieu of a *Welcome to Country* (see Glossary), there has been a suggestion by Elders to invest in Welcome to Country blankets for the beds of Aboriginal young people and their families. These blankets would be a traditional patchwork rug made from possum pelts, on which the hide side is etched with markers of Country. Two of the Elders involved in developing the Aboriginal Knowledge Place strategy have been involved in making possum skin cloaks with young people in out-of-home care as part of a community healing program (<http://www.vacca.org/services/strengthening-culture/possum-skin-cloak-project-2013/>). Another Elder has been instrumental in developing *yarning* circles (see Glossary) in community, which are focused on women’s cultural identity, men’s cultural identity, lateral violence, domestic violence, alcohol/substance abuse disorders, and parenting skills to foster the next generation.

Ideas for transforming the space of the hospital include: Welcome to Country floor murals and plaques at the hospital entrance and an Indigenous garden in the outdoor area adjacent to Wadja Aboriginal Family Place. The garden would have medicinal plants, spaces for

smoking and water ceremonies, and places for storytelling, deep listening, and healing practices. This would be the starting place for Aboriginal health trails that could be developed in Royal Park, the gardens where the hospital is situated. A number of community organisations have been involved in projects where walking Country is used as a health-based practice (Mitchell, 2012). Already, young people and their families served at the hospital are being referred to on-Country learning walks that are conducted by senior Aboriginal people and Elders at various rural locations in Victoria.

Conclusion

The Aboriginal Knowledge Place model is nested within a larger dialogue led by Aboriginal leaders nationwide. A national action plan to address Indigenous youth suicide in Australia is imminent (Brennan, 2015). The *Elders' Report into Preventing Indigenous Self-Harm and Youth Suicide* (People Culture Environment, 2014) has emphasised the same all-encompassing connection between culture, health, healing, and resilience for Australian Aboriginal people. It is important to establish a systematic database to record, organise, and foster this future development. If findings of Indigenist–Western health dialogue continue to show promise, the model of an Aboriginal Knowledge Place could be extended to other hospitals around Australia. Qualitative and quantitative data collected pre- and post-intervention and randomised controlled trial evaluations will be crucial. The Binaḡ Goonj (Eckermann et al., 2006) initiative is appropriate because it articulates the need for economic, political, and social agency in order for Indigenous communities to be healthy. A database which emerges from the Aboriginal Knowledge Place could provide an important line of evidence for funding so that hospital outpatient-based health and mental health management can extend into each Aboriginal young person's community of origin through an advocacy model built on genuine and explicit dialogue. Future teaching programs based on the lessons learned from the action–reflection Indigenist dialogue need to inform extant hospital policy, clinical practice, academic domains, and Aboriginal communities. If all of these objectives can be achieved, hospitals will be nurtured by Aboriginal Knowledge Places that support deep responsive listening and transforming dialogue for the benefit of all—Aboriginal and non-Aboriginal alike. The literature on mental health and architecture published in the last decade reveals that the connection between health and living environments is not confined to those with Aboriginal heritage. Perhaps Indigenous ways of knowing and being provide a timely critique of the configuration of space for the delivery of Western health care for all.

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***Kiskenimisowin* (self-knowledge): Co-researching Wellbeing With Canadian First Nations Youth Through Participatory Visual Methods**

Abstract

Indigenous youth represent one of the most marginalized demographics in Canada. As such they must contend with many barriers to wellness that stem from oppression, including historical and ongoing colonization and racism. Developing effective health programming requires innovation and flexibility, especially important when programs take place in diverse Indigenous communities where local needs and cultural practices vary. This article reports the findings of an after-school program in 2014 that blended a participatory visual method of research with Indigenous knowledge, methodologies, and practices to provide sociocultural health programming for youth in a First Nation in southern Saskatchewan, Canada. Engaging with youth to co-research wellbeing through the arts was conceptualized as both research and health promotion. Participatory arts methods created a safe space for youth to express their views of health and wellness issues while developing self-knowledge about their individual and cultural identities.

Keywords

Wellbeing, Indigenous methodologies, participatory visual methods, visual arts, self-knowledge, identity, Indigenous youth

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¹ Our research team was saddened by the passing of our colleague Dr. Episkenew in February 2016. She was integral to our research and contributed to this article before she began her spirit journey.

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Introduction

Kiskenimisowin is the Cree word for “knowing oneself.” In the Cree language, the medial stem “iso” indicates a focus on self or self group² and the activity within. One comes to know oneself through interaction with the self (introspection, self-reflection) and the world around oneself. Creative forms of communication using tools (art materials and techniques) and others to assist that creation leads to exposure and expression of the self in all dimensions (physical, spiritual, mental, socio-emotional). (K. Goulet,³ personal communication, September 7, 2014)

Health research is undergoing a shift such that how we view health and engage in health research is becoming more open to alternative definitions, perspectives, and practices. The biomedical model of health that considers illness with minimal account of psychological and social factors is shifting in the face of a growing recognition that health has sociocultural determinants (Raphael, 2006). New research methodologies are now being recognized for their potential contributions to health knowledge. Participatory visual methods are participant-centred, image-based techniques that “facilitate participants in finding their own language to articulate what they know and help them put words to their ideas and share understandings of their worlds, thereby giving participants more control over the research process” (Enright, 2013, p. 216). These methods can shift the conventions of research authority by empowering participants to express their own interpretations of their lived experiences.

Arts-based research and programming can be used to promote health and wellness. They have potential for meaningful engagement with youth. Cultural arts programs with non-Indigenous youth labelled “at risk” and experiencing mental health challenges have

² “Self-group” is a Cree concept of the plural form of self. It refers to any form of identifiable collective unit or self identified group, for example a small group, an extended family or a nation.

³ Keith Goulet, a fluent Cree speaker, is an adjunct professor in Indigenous Studies at First Nations University of Canada and a former educator and provincial cabinet minister. He grew up in a traditional lifestyle of hunting, fishing, gathering, and trapping in the Nehinuw (Cree) community of Cumberland House, Saskatchewan.

demonstrated positive outcomes in terms of anger management, life skills, and pro-social attitudes and behaviours (Rapp-Paglicci, Stewart, & Rowe, 2009). Indigenous youth also respond well to arts programming (Flicker et al., 2014; Goulet, Linds, Episkenew, & Schmidt, 2011; Yuen et al., 2013) when participatory visual methods are done from a decolonizing perspective that eschews colonial tendencies to focus on deficits, labels, and measurements (Linklater, 2014). Arts-based programming as research has dual purposes that inform each other. One purpose is to explore the lives and experiences of participants while the other acknowledges that this form of exploration is an inter-subjective and potentially transformative process that can enhance wellbeing (McNamee, 1988).

Health promotion in Indigenous communities must be considered holistically within the context of colonization, which has oppressed and damaged Indigenous Peoples' economic and social systems. Colonialism continues to be enacted in relationships of power and privilege that have been constructed historically through many means, including war, law, policy, theoretical constructs, and the media (Anderson & Robertson, 2011; Episkenew, 2009; Goulet & Goulet, 2014). The trauma caused by colonization as well as ongoing racism and micro-aggressions continue to affect the health of Indigenous people (Chae & Walters, 2009; Currie, Wild, Schopflocher, & Laing, 2015). Despite these stressors, Indigenous people have protective buffers such as language and culture to aid in their resistance to ongoing racism and colonialism (Chandler & Lalonde, 2009). The reinforcement of strong individual and cultural identities, combined with systemic change such as the decolonization of institutions, social structures, and mentalities, is important in addressing health issues in Indigenous communities (Czyzewski, 2011; Kirmayer, Tait, & Simpson, 2009).

Indigenous knowledge identifies a local system of being, knowing, and expressing inculcated into all aspects of a society's knowledges, language, and practices (Settee, 2013). In the Cree language, *pimatisiwin* translates as "life," while *pimachihowin* is "lifelihood action." David Benjoe, a visual artist and educator and co-author of this paper, explains how self-knowledge is embedded in concepts of a healthy life:

You can go through all the descriptions of what makes a human being whole, but in our languages we usually just said life. It was just pimatisiwin ... When it comes to health, you have to have an understanding of who you are and where you fit in terms of your understanding of the world. So it becomes well rounded. It becomes, as people say, holistic. ... Health is ... not just about [being] physically healthy, there's also mentally healthy too. And emotionally healthy.

Pimachihisowin is the self-determined action of individuals, groups, and nations in the quest for life, livelihood, and survival; it too refers to "life" but with the middle stem—*ihiso*—signifying the self-determined intentionality of an individual or self-group (Goulet & Goulet, 2014). Individuals and collectives are understood to have the authority to interpret what constitutes good living and how such states can be sought and maintained (Heritz, 2012). Indigenous

knowledge recognizes that artistic endeavours are part of life, promoting and sustaining health and wellness.

Historically, the creative arts were particularly important to Indigenous people. The ancient rock art, or *asinapiskuhigehin*, of the Cree people used power-based symbols to represent life forces of the universe. Cultural symbols continue to be of central importance to the cultural identity of the Cree (K. Goulet, personal communication, September 7, 2014), whether as a form of cultural expression and/or as part of healing activities (Archibald & Dewar, 2010). Armstrong (2002) wrote, “Aboriginal arts are a necessary facet of individual and community health, containing symbolic significance and relevance integral to the deconstruction of the effects of being colonized ... [r]einforcing the reconstruction of what is precious” (para. 19).

Artistic expression is one means through which humans acquire a sense of wholeness. Traditional song and other embodied forms of expression such as dance and drawing can reconnect Indigenous people with their inner spirits, the earth, and other relations, contributing to a sense of renewal and strength (Goudreau, Weber-Pillwax, Cote-Meek, Madill, & Wilson, 2008; Nadeau & Young, 2006). The arts are how we learn about, come to terms with, and express our identities, emotions, thoughts, and spiritualities. Cultural arts transmit traditional knowledge but they also promote embodied healing as individuals become absorbed in tasks, perform rhythmic physical movements, and participate in the reinforcement of social bonds (Lincoln, 2010).

This article details the outcomes of an after-school visual arts program that was developed as a culturally appropriate means to promote wellbeing among First Nations youth. It is part of a larger project in wellness promotion where engagement in the creative arts is used to facilitate self-expression, leadership skills, and healthy decision-making. The focus of this paper is to demonstrate the efficacy of arts-based activities both for wellness promotion and as a research method. This project uses a form of research that draws upon the local Indigenous knowledge of the participants to decolonize racialized societal representations while developing youth-inspired notions of wellbeing.

Project and Methods

We are a collaborative research partnership of Indigenous and settler scholars and health professionals who have been working in partnership since 2005 with File Hills Qu’Appelle Tribal Council (FHQTC) Health Services. FHQTC serves 11 First Nations from five cultural and linguistic groups situated in southern Saskatchewan, Canada. One goal of our overarching project, called “Acting Out! But in a Good Way,” is to explore how arts-based work grounded in Indigenous values and practices improves First Nations youths’ sense of wellness and wellbeing, and how arts-based Indigenous methods have an impact on youths’ health choices and actions. Based on an Indigenous view of wholistic health, we blend Indigenous knowledge and relational practices with participatory visual methods in urban and First Nation locations. Visual arts, participatory video production, and applied theatre are used to develop positive relationships and

enhance feelings of wellbeing in the physical, intellectual, social/emotional, and spiritual domains.

Our work is informed by multiple influences that we apply in the contexts of arts, education, and health. Theories of colonization-decolonization point to decolonization as involving the critical identification and dismantling of structures, ideologies, and mentalities that devalue, minimize, or subjugate Indigenous ways of knowing and living, combined with the restoration of Indigenous cultural knowledge and practice (Episkenew, 2009; Graveline, 1998; Linklater, 2014; Smith, 1999). Decolonizing theory challenges terms like “at risk” and “intervention” for they imply individual deficits or pathologies to be fixed, rather than understanding the oppressive colonial structure as the source of health disparities (Czyzewski, 2011). Indigenous research methodologies centralize relationships and self-knowledge (Absolon, 2011; Kovach, 2009; Wilson, 2008). Furthermore, the arts enable an embodied process of interaction in which alternative futures can be modelled and transformed through an aesthetic and playful process within a creative space (Boal, 1979; Fay, 1987; Meyer, 2008). Our use of participatory visual methods offers youth a wholistic medium through which they can develop self-knowledge, thus becoming researchers into their lives.

Indigenous methodologies value self-knowledge and subjective experience (Absolon, 2011). They are effective for wellness promotion because the emphasis placed upon self-determination decolonizes identities and relationships (Heritz, 2012; Smith, 1999). Legitimizing individual subjectivity and experience reasserts the value and authority of traditional Indigenous ways of being. Research methodologies directly impact the development of the researcher–participant relationship, so the strong valuation of relationality inherent to Indigenous axiology means that research must make relational accountability a priority (Wilson, 2008).

Multiday drama workshops that were implemented in different communities during earlier stages of the larger project developed positive relationships and health leadership skills with Indigenous youth (Goulet et al., 2011; Yuen et al., 2013). However, there was a need to assess the impact of arts programming on youth wellbeing across a longer period of time than 3-day workshops. Our community partners and our Elders’ Advisory Circle asked the research team to offer after-school arts programming for junior high and high school students. Our research partner then communicated the possibility of arts-based research programs to the different schools in the Tribal Council area. This article is based on one such 4-month program that took place as an after-school arts class in an Anishnabe and Nahiyawak (Cree) community from November 2013 to June of 2014.

Youth were invited to attend the after-school arts class with the understanding that it was connected to a research project. Based on ethical approval from the University of Regina and the FHQTC, consent to participate in the research was obtained from the youth or their parents/guardians. Participating youth and the program facilitators generated data. The facilitators were two male community research associates (David Benjoe and Dustin Brass), originally from nearby Anishnabe and Nahiyawak reserves. Both facilitators were experienced high school teachers with expertise in culturally appropriate arts programming. A non-

Indigenous female postdoctoral fellow (Mamata Pandey) sometimes accompanied them. Together, the program facilitators guided group-building activities, taught visual art techniques, held discussions on the topics of identity and wellbeing, and conducted talking circles with youth that typically focused on a health-related theme. Storytelling and sharing circles were used in the project primarily to emphasize relationality and subjective experience (Archibald, 2008; Kovach, 2009).

Program facilitators maintained an audio diary of field notes about their observations of the youth and other experiences implementing the program. These field notes were often recorded as post-session debriefing conversations. At the end of the program, 13 youth—seven female and six male—consented to be interviewed about their art, their experiences of the program, and their ideas about wellbeing. The interviews involved some semi-structured components but also included unstructured conversational interviewing to preserve the authenticity of the interaction (Absolon, 2011). Field notes and interviews were transcribed and analyzed by the program facilitators to discern key features and identify themes arising from the data.

Fourteen youth participated in the weekly program; most identified as Cree. Two youth were in Grade 8, and 12 were in Grades 10 or 11. All students who attended received school credit towards their applied arts class regardless of whether they agreed to be interviewed. This article presents the voices of six of these youth: Jenna, Schmidt, Ashley, Luke, Laurel, and Prentice.⁴ Jenna expressed a desire to study law in university. Schmidt liked dancing, listening to music, playing volleyball, and hanging out with friends, all of which helped her “feel better about [her]self.” Ashley loved art. Her father was a well-known artist who had a strong influence in her life. Luke talked about becoming a computer technician. He used to dance in powwows and enjoyed basketball, hunting, and hanging out with friends. Laurel was skilled at beading and talked about how her family passed traditional teachings on to her. Prentice had an interest in carpentry.

Results

The youth were co-researchers in this program because the activities stimulated their discovery of self-knowledge. As academic co-researchers, we were interested in what this self-knowledge was and how the artistic process contributed to its discovery. The results of this research are presented in terms of the outcomes of artistic processes and the discoveries that youth said they experienced.

Respectful Relationships: Using Art to Create a “Safe Enough” Space

Foundational to effective pedagogy for Indigenous learners are respectful relationships (Goulet & Goulet, 2014) and the creation of a “safe enough” space for learning (Khaner & Linds, 2015). This study confirms that the arts, along with the process of visual participatory methods,

⁴ Participants’ names are pseudonyms, some of which youth chose themselves.

can facilitate the emergence of a safe space while offering a means to safely deal with difficult or traumatic experiences (Archibald & Dewar, 2010). Ensuring a safe enough space is necessary to encourage youths' self-discovery process. Cultural safety in any program involves the redistribution of power so that the knowledge, values, and belief systems of Indigenous Peoples are prioritized in any initiative, practice, or relationship (Brascoupé & Waters, 2009). Indigenous knowledge, pedagogy, and values were centralized throughout the process. However, a culturally safe context does not guarantee an emotionally safe context if participants do not have the confidence to try new things, particularly if they are risking ridicule from their peers. Consequently, program facilitators took the time to build relationships of reciprocal respect and trust with participants, and to reinforce respect between participants. They made conscious efforts to create a safe space within the group characterized by respect: "The important thing ... is to show that ... we care genuinely and are not here for the sake of collecting data" (Mamata, field notes, March 3, 2014). Respect was demonstrated by listening to youth and expressing interest in their viewpoints, which also reinforced the message that the youth should be respectful of themselves.

Respectful relationships promote trust. Trust formed as facilitators paid attention to and adjusted their behaviour to meet the needs of the participants. For example, Mamata reflected early on in the program:

I didn't talk very much today because there were a lot of new people and I wanted them to get settled with the art concepts first before we started talking a lot about the research. ... But that's ... a matter of building that relationship and making them comfortable, and not pushing them into doing something that they're not ready for. (Field notes, March 3, 2014)

Doing art requires risk taking, so trust and safety are important aspects of working with the arts and wellness. Engaging in applied theatre with refugee youth in Australia, Hunter (2008) demonstrated that safe space connotes metaphorical safety, where a space that has a specific time or place—much like the after-school art program—instills a sense of comfort and familiarity. The space is just safe enough to take risks in that moment of putting the brush to the canvas or the marker to the paper, and this safety is facilitated by the ambiguity of artwork such that youth can be self-expressive without fully disclosing the contents of their thoughts. In one class session, David was telling the students about how "we're going to use symbols to talk about your story" in the following week. Observing the youth, Dustin indicated the following in his field notes:

Some of the students were wondering about if they should be sharing their full story and their true story. David responded, "Well, that's why you use symbols and we're not asking you to talk in front of everyone." It seemed like there was kind of an ease after that was said. (Field notes, March 31, 2014)

The visual arts in this project were bridged with storytelling so that youth could express their subjectivities within the safety of metaphor and nuance.

The Development of Art Skills and Cultural Values

There is a pedagogical process to art education that encourages students to grow beyond just technical skills. This project gave youth a chance to work with new materials and learn new art techniques, including drawing, painting, and comic book storyboarding. The development of artistic abilities created transferable skills to be used in other life situations, such as planning and story sharing for life learning. Working on a particular piece became a metaphor for other life tasks, which gave the participants a level of competence and instilled confidence. In the program, participants had opportunities to engage in life lessons pertaining to decision-making, perseverance, and even basic values like respect and appreciation. Planning and deliberation are important parts of decision making in visual arts that become readily apparent when undertaking larger projects. Without them, artists will likely encounter unanticipated errors or challenges to their project. Learning to persevere and adjust for these occurrences was part of the artistic process. Luke shared that drawing made him feel good. When pressed as to why, he said, “I draw cool things. Like, things that I never tried drawing before. If I were to start drawing and make a mistake on it, I’d turn that mistake into something else.”

One activity required participants to do a series of timed blind contour drawings where youth were not allowed to look at or lift the pencil from the surface of their paper as they copied simple images. In their interviews, David asked youth to reflect on this activity and consider the broader life lessons embedded within.

David: *Explain to me what I [had you do].*

Jenna: *You just drew four sketches on the board and then you told us to draw one, each, and one we were getting timed on and we only had to do the outside of the sketch. And then I ended up doing the easy ones first and then it progressed into being, the time limit being shorter [David laughs] and then I had the hard ones to do last.*

David: *What did that teach you?*

Jenna: *Not to take the easy things first [both laugh].*

As an educator, David designed the art lessons in such a manner to challenge youth while retaining the playfulness of the activities.

The program challenged youth to test out new experiences and to engage in a learning process as they were provided new materials, activities, and projects. The lessons that students took from this process went beyond the superficial technical aspects to a deeper philosophical and value-based learning, such as the use of colours in relation to the medicine wheel or to define one’s sense of self. Laurel reflected:

When we first started out, I kind of didn’t like the whole ... drawing thing. But once you started getting the materials and stuff, I got more comfortable with the art and wanted to

do it more, because there was just so many other materials to use, instead of just using, like, one ... But I do understand how you wanted us to get, like, a lesson each time so that we know how to respect the materials and stuff because those were given to us by you guys.

The uniqueness of this arts-based program may be attributed to the Indigenous approach to experiential and relational learning. This approach is evident in David's interviews, in which youth were encouraged to reflect on what they were learning about themselves through their art.

Expressing Cultural and Individual Identities

Art is a traditional form of expression for Indigenous Peoples that links culture, self, and wellness through confidence building and the exploration of identity (Archibald & Dewar, 2010). Some of the youth picked up on this resonance between selfhood and art:

We all have our own story and we have, like, our own understanding of stuff. So if you were to put it into your artwork, like, that's what creates it, like your own piece and your own personality and your own feelings. Like everything you do goes into your art.
(Laurel)

Identity is not limited just to individuals. It involves feelings of belonging, shared group values, and differentiating oneself from others, so it is "formed and shaped through a process of mutual constitution with others and within various social and cultural contexts" (Schouls, 2003, p. 425). This topic emerged early in the program as the facilitators observed youth conversing during the activities:

I was starting to notice the words that [some boys] were producing were about identity, so ... when they would throw out a term, even if they just did it as teenage boys do and blurted it out, I wanted to address it. Later, I'd either bring it up in a conversation or talk about it right there. But I'm starting to find that they're starting to look at identity and what does that actually truly mean. (Mamata, field notes, March 24, 2014)

The relational aspect of identity is the reason it is important to conduct this type of programming in a group setting. The process of natural group interactions in a safe enough space facilitated the exploration of identity between peers that was readily observable by the program facilitators.

Artistic self-expression revealed the connection between participants' individual identities, their cultural teachings and activities, and the close relationships they had with familial role models. Schmidt drew from her knowledge of the Cree language to produce her comic storyboard (Figure 1). Some participants had familial role models that directly inspired their engagement in art and drew their attention to the connection between art, relationships, and wellbeing. Ashley was one such youth:

The big eagle that my dad made would bring me back to him making that while I'll be making this. ... Putting almost, like, every day into his artwork and he would just, like, get lost in his work and everything. He wouldn't know what time of day it is because he would get lost in it every time.

These connections to culture and family are central to youths' wellbeing. Having a strong sense of self and cultural continuity, so that a person can visualize possible or hoped-for futures, is a key factor in maintaining feelings of belonging, fostering resilience to adversity, and preventing suicide in Indigenous youth (Chandler & Lalonde, 2009).

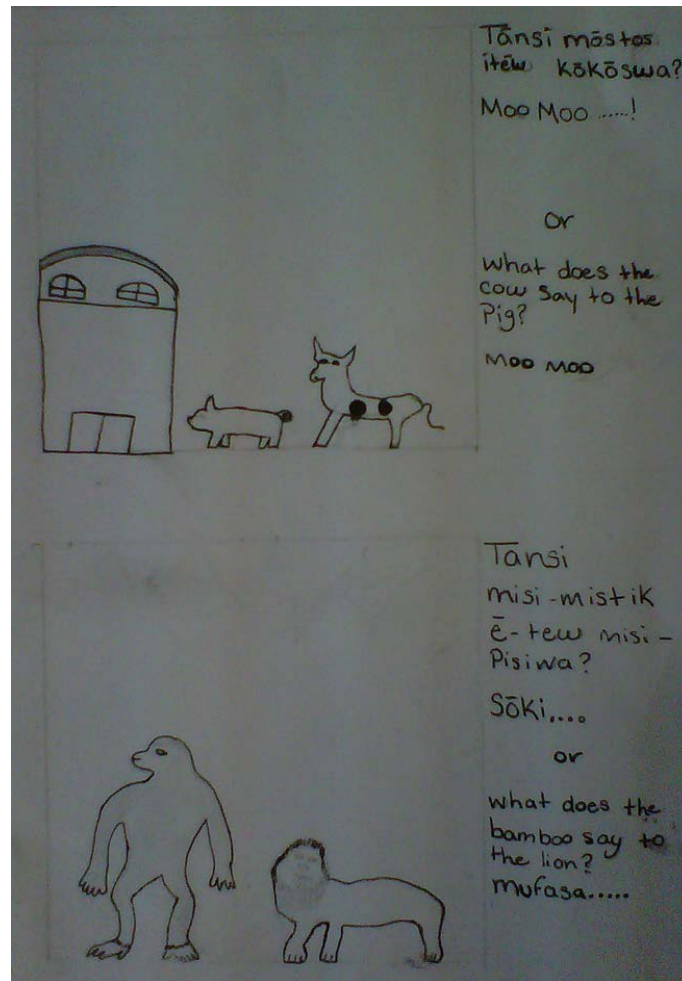


Figure 1. Comic storyboard.

Laurel drew a collection of images that included a traditional dancer with flowers and a geometric design (Figure 2). When explaining the meaning of her work, she made clear connections between culture, identity, and cultural continuity. Laurel spoke of traditional teachings and her relationship with her grandfather: “I was taught, like, if you were to have a dream about something, like a type of design or ... jingle dress, you have to draw the design right

away, so you won't forget. And then [you can] ... make use of that design." When David inquired about her choice of composition, Laurel explained:

I remember having that dream of that [geometric] design that was at the top of the paper so I wanted to include it in there ... I wanted this [picture] to kind of represent myself because my Indian name is "[___] Woman." So my animal, my grandpa said it was the horse, and if I was ever to bead something or make something for myself to always include something with a horse in it. And the flowers just ... represent the earth.



Figure 2. Traditional dancer.

In our experience, participation in arts-based programming can facilitate youths' self-knowledge through their self-expression, the navigation of technical challenges, and discussions or other social interactions occurring in the context of one's work. For some participants, that self-knowledge was connected to a sense of place within the community and the natural environment. Ashley described her artwork:

It's a wolf sitting on a hill and trees surrounding it, pine trees. It's very dark out. There's a tree leaning towards the wolf and I made it kind of look like northern lights, touching the sky, kind of going from dark to light.

"Why a wolf?" David asked. "Because," Ashley responded, "it kind of represents the reserve. Represents, like, me." Ashley's description of her wolf symbolism underscores how closely connected individual and cultural identity is interwoven in her identity. The wolf seems to

represent both herself and her First Nation community, both coexisting as two inseparable entities. Sense of place is an important part of identity, and particularly so for many Indigenous people (Wilson & Peters, 2005). In Ashley's picture, she placed herself within the natural environment of her First Nation, which suggests her sense of self is connected to a sense of place filled with natural beauty. Self-knowledge was clearly connected to cultural identity and the important relationships youth had in their lives. While it was at times difficult for youth to explain why they produced the art that they did, it is evident they were drawn to more symbolic means of self-expression that asserted their identities as Indigenous people and maintained cultural continuity.

Decolonizing Racialized Representations

Art also gave participants a means to challenge colonized images of Indigeneity and reconstruct culturally appropriate images. Jenna had recently watched the documentary *Reel Injun* (Diamond, Bainbridge, & Hayes, 2009), which details how Indigenous people have been represented by the film industry. Consequently, she decided to reimagine Disney's stereotyped and sexualized representation of an "Indian princess" into an image that was much closer to her experience as a young Cree woman. David asked Jenna what stood out for her in the program:

I guess expressing yourself. 'Cause I remember I did a picture of a modern Pocahontas and I drew her body and figure and everything. But I put different clothes on her. I put a ribbon skirt on her and she had a long-sleeved shirt on and she, like, wasn't so skanky⁵ looking like she is in the actual movie.

Jenna described her version of Pocahontas as "more modern ... wearing beading ... moccasins ... and standing in the woods." Jenna's Pocahontas reflected a contemporary cultural identity that retained traditional cultural markers while negating the too often hyper-sexualized representation of Indigenous women and the "Indian princess" stereotype.

Schmidt also challenged the lack of positive images of Indigeneity in popular culture. She created a comic book character called "Super Native" (Figure 3) and described her thoughts about her creation:

That's pretty cool, adding the Aboriginal ... culture into it because you don't really see comic books of Aboriginals. It's always about, like, the white people and their ways and their jokes. So I just figured that I'd try to add my own, and just try to put it into there.

By using their art to challenge the lack of positive images of Indigenous people in the mainstream media, youth appeared to be taking control of their own decolonizing processes as their self-knowledge expanded.

⁵ *Skanky* is slang for immoral or promiscuous.

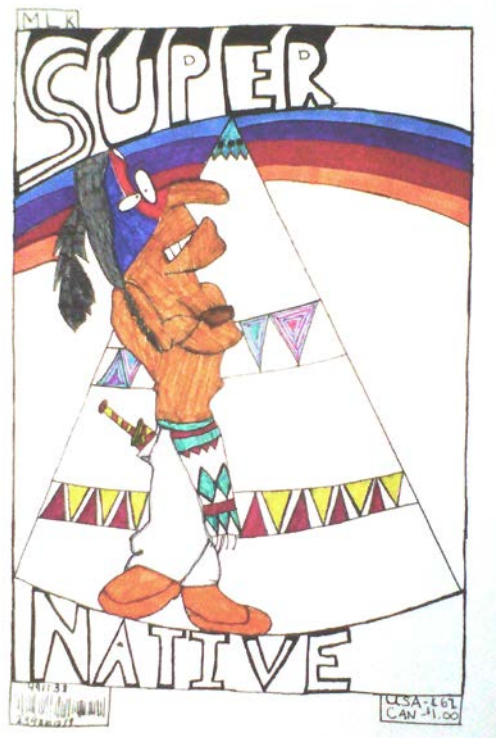


Figure 3. Super Native.

Program Impact on Wellbeing

The arts program was well received by youth. Overall, youth indicated that their participation induced positive feelings. Jenna said, “It gave me something to look forward to, to come to school and that you are going to be doing something with your hands and get dirty and have fun.” Youth could reveal feelings that they would not normally express. When asked to describe how art contributed to his wellbeing, Prentice said, “When I was drawing a picture, all the things I couldn’t say to anyone were in the picture.” Some participants made direct connections to self-expression and mental wellbeing. When asked about the benefits of art, Laurel responded, “Yeah, it helps sometimes. Like when you have so much on your plate and you kind of just, like, want a break and everything. It just helps, like, for you to express your feelings into, like, a piece of art.”

Laurel intuitively recognized how participation in arts activities facilitated resilience by providing a means of coping with personal difficulties. She demonstrated insight and self-knowledge that was connected to her previous experiences of artistic expression through the traditional activity of beadwork.

[Beadwork] is something I really excel in and ... enjoy. ... It, like, relaxes me. ... Some people say, “Oh, it’s so time consuming and it’s so hard.” But ... if you’re going to balance out everything and, like, be able to do the stuff you do, like, you’ve got to have a

balance to everything. Because you can get so lost in a project and just, like, forget about it.

Maintaining balance between the different aspects of our lives is a core value of Indigenous conceptions of wellbeing (Hart, 2002). Laurel understood the benefits of artistic practice because she already engaged in different artistic endeavours. Other youth, however, may not have had such opportunities owing to dramatic underfunding for any academic programming in First Nations communities, let alone arts-based programming (Chiefs Assembly on Education, 2012). This project was able to bring the arts to youth who might not otherwise have been able to learn about visual arts techniques and thus also exposed them to the connection between wellbeing and the artistic process in a manner that facilitated the growth of their self-knowledge.

Reflections and Limitations

Arts-based research is important for documenting successful health activities and effective research strategies, and for communicating the effectiveness of the arts in health education with Indigenous youth. Although arts-based programming is a promising research method that can promote self-knowledge and wellbeing among Indigenous youth, it is important to note that this program was developed within a particular context, and any future applications should consider the community's and the youths' unique situations and histories. The success of this programming was very dependent upon the facilitators' experiences and cultural knowledge that enhanced the programming and the relationships they developed with and among the students.

Although positive short-term outcomes were evident, our goal to identify longer-term outcomes of arts programming on wellbeing remain elusive. We recognize that longer follow-up time is required to document long-term effects of visual arts programming. Also, because this research is based on a small group of mostly Anishnabe and Nahiyawak (Cree) students, ideally it could be scaled up to more communities and students, preferably with additional cultural backgrounds.

Concluding Comments

Wellness promotion through participatory visual methods engages youth in programming that promotes the development of *kiskenimisowin* (self-knowledge). Arts activities have potential to connect with Indigenous youth in ways that can complement conventional research methodologies as youth are empowered to make their own meaning of their lives. The arts provide the skills and a safe enough space for youth to partake in self-expression, to discover their individual and cultural identities, and to consider the meanings of their cultural expressions in the context of positive social interactions with peers and adult role models. These findings build upon the beneficial outcomes already noted in other arts-based programming for Indigenous youth.

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