

PARTICIPATORY FILMMAKING AND HIV/AIDS EDUCATION WITH
INDIGENOUS YOUTH IN LABRADOR: EXPLORING KNOWLEDGE/ATTITUDE
CHANGE AND THE EXPERIENCES OF INDIGENOUS YOUTH AND ELDERS

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Abstract

Arts-based HIV/AIDS education initiatives with Indigenous youth have become increasingly popular; however, little research addresses their development, effectiveness, and acceptability. This dissertation describes and evaluates a participatory filmmaking and HIV/AIDS education workshop for Indigenous youth in Labrador.

Guided by decolonizing principles and adopting a community-based research approach, I collaborated with an Indigenous community organization to develop, implement, and evaluate an arts-based HIV/AIDS education workshop. Workshop participants included eleven youth, ages eleven to seventeen, and five Elders who self-identified as Indigenous. Participatory filmmaking was used to engage participants and create dialogue about HIV/AIDS, sexual health, and health in general. The participants created four films during the 3.5-day workshop.

A mixed methods approach was used to evaluate the youth's HIV/AIDS knowledge and attitude change post-workshop and to explore the experiences of the youth and Elders. Youth completed a pretest and posttest comprised of the HIV-Knowledge Questionnaire (HIV-KQ-18) and "Your Beliefs" attitude questionnaire immediately before and after the workshop. Approximately two weeks after the workshop, participants were interviewed about their experiences.

Analysis of pretest and posttest data using matched t-tests supplemented by Wilcoxon sign rank tests demonstrated that the youth significantly improved their HIV/AIDS knowledge and attitudes after the workshop for HIV-KQ-18 knowledge scores ($t_{(9)} = 8.093, p < .001$) and "Your Beliefs" attitudes scores ($t_{(9)} = 3.674, p = .005$).

Content analysis of interview transcripts showed that youth participants: learned about HIV; learned about stigma; operationalized new knowledge; learned about healthy relationships; and attributed their knowledge and attitude change to their experience at the workshop. Additional findings include: the youth found participatory filmmaking an acceptable and engaging strategy for HIV/AIDS education; participatory filmmaking allowed youth to create an educational environment; the process of participatory filmmaking facilitated the development of relationships between youth and between youth and Elders; and the youth viewed themselves as HIV/AIDS educators. Analysis of the Elders' interviews showed that they found the participatory filmmaking process to be a “comfortable” experience; they found the workshop to be a learning environment; and they found that the workshop facilitated relationships between youth and Elders.

These findings suggest participatory filmmaking is a promising arts-based approach for HIV/AIDS education with Indigenous youth, providing a good platform for constructive dialogue and engagement among youth, and between youth and Elders. Developing successful strategies for improving HIV/AIDS knowledge and attitudes is essential to addressing the overrepresentation of Indigenous youth affected and infected by HIV/AIDS in Canada.

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List of Abbreviations and Symbols

AIDS Acquired Immune Deficiency Syndrome

CIHR Canadian Institutes of Health Research

CBR Community-based Research

DVD Digital Versatile Disk

FOXY Fostering Open eXpression among Youth

HBM Health Belief Model

HIV Human Immunodeficiency Virus

HON Healing Our Nations

HV-GB Happy Valley-Goose Bay

IBM Information Motivation Behavioural Skills Model

LFC Labrador Friendship Centre

NL Newfoundland and Labrador

NL HREB Newfoundland and Labrador Health Research Ethics Board

STBBI Sexually transmitted and blood-borne infection

STI Sexually transmitted infection

TPA Theory of Planned Action

TCPS II Tri-Council Policy Statement II

WHO World Health Organization

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Co-Authorship Statement

To the best of my knowledge, this dissertation does not infringe on anyone's copyright. I am the sole author of this dissertation.

1. Introduction

In Canada, there is a need for culturally-relevant, engaging, and effective HIV/AIDS education for Indigenous youth, as Indigenous people face a disproportionate burden of disease, including overrepresentation in rates of HIV infection (Adelson, 2005; Gracey & King, 2009; PHAC, 2014). Health disparities between Indigenous and non-Indigenous populations are fuelled by factors such as the ongoing legacy of colonialism (Adelson, 2005; Gracey & King, 2009; Greenwood, De Leeuw, Lindsay, & Reading, 2015). For example, poverty, racism, and intergenerational trauma as well as the loss of autonomy, self-governance, traditional ways of life, and lands contribute to poorer health outcomes among Canada's Indigenous peoples, including higher rates of HIV infection (Flicker et al., 2014). Traditional public health approaches that do not account for the unique factors (such as the impact of colonialism) that increase the risk of HIV transmission and determine health for Indigenous people are not adequate for addressing HIV/AIDS within Indigenous populations (Flicker et al., 2014; Steenbeek, 2004). Innovative health promotion strategies that address the determinants of Indigenous health and factors that increase the risk of HIV infections must be developed in order to curb infection rates (Flicker, 2013). In particular, prevention strategies for Indigenous youth should address the social factors that contribute to the elevated risk of HIV infection for Indigenous youth (Flicker et al., 2013).

Arts-based initiatives have emerged as promising strategies for health promotion in recent years with a variety of populations (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012). Genres of art, such as painting, music, and theatre, have been used in

health education initiatives such as education on stroke, hand hygiene, heart disease, chronic pain, tobacco use, and sexual health, with target audiences including children, youth, adults, men, and women, all around the world (Boydell et al., 2012a; Williams & Noble, 2008). Arts-based education initiatives have also been increasingly used as strategies for HIV/AIDS prevention with Indigenous youth in Canada (Ricci, Flicker, Jalon, Jackson, & Smillie-Adjarkwa, 2009).

Although there are many initiatives that use arts-based approaches for HIV/AIDS education and prevention, there is little research available discussing their use, development, appropriateness, effectiveness, and acceptability. Additionally, arts-based programming has challenged some of the traditional strategies for evaluation (Boydell et al., 2012a).

1.1 Thesis overview

This dissertation describes a community-based research (CBR) project that explored the use of the arts as a strategy for HIV/AIDS education with Indigenous youth in Happy Valley-Goose Bay, Labrador. This thesis follows manuscript style and is comprised of an introduction to the thesis, three manuscripts based on research findings, and a conclusion that ties the manuscripts together. This introduction provides an overview of my thesis, the research project, a review of the literature, and the development of the arts-based HIV/AIDS education workshop. The introduction is followed by three manuscripts prepared for publication, which highlight the main findings arising from this research. The first manuscript uses a mixed methods approach to describe changes in the youth participants' HIV/AIDS knowledge and attitudes over

the course of the participatory filmmaking workshop. This manuscript has been accepted for publication in the December 2018 issue of the *Journal of Indigenous HIV Research* (see Landy, 2018). The second manuscript uses a qualitative approach to share the youth's voices and describe the youth's experiences participating in a participatory filmmaking and HIV/AIDS education workshop. This manuscript has been submitted for publication. The third manuscript uses a qualitative approach to share the voices, perspectives, and experiences of community Elders participating in an arts-based HIV/AIDS education program for Indigenous youth. This manuscript has also been submitted for publication. These manuscripts are followed by a conclusion that sums up the research findings, limitations, and the implications of this research.

The manuscript format was chosen as it facilitated timely publication of study results and supported scholarly writing skills development. The three manuscripts present three different aspects of evaluation of a community-based, participatory filmmaking, and HIV/AIDS prevention initiative. Given the nature of manuscript format, the reader may find that some detail or depth may be abbreviated in these manuscript chapters; thus, the introductory and concluding chapters of the thesis provide important background and reflection and synthesis information. As well, the reader may find the required contextualization of the research and literature reviews underpinning the project that are outlined in each manuscript to be repetitive.

1.2 Terminology

In Canada, the term Aboriginal has been used to refer to Inuit, Métis, and First Nations Peoples. Inuit, Métis, and First Nations Peoples refer to groups of people who are

legally recognized by the Canadian government; however, these terms are often also used to refer to people who do not have legal status. When I began my doctoral research, the term Aboriginal was used favourably in Canada to refer to Inuit, Métis, and/or First Nations Peoples with or without status. Recently, there has been a shift away from the term “Aboriginal” to the term “Indigenous” as it has fewer colonial connotations and represents First Peoples globally (Institute for Indigenous Peoples’ Health, 2013). Additionally, the term Indigenous is often used in international contexts. The terms Indigenous and Aboriginal are used interchangeably throughout this thesis to refer to people who have Indigenous status or who self-identify as Indigenous or Aboriginal. I use the term Aboriginal when it is used in the source I am referencing, when it is used by an organization in their name such as the Canadian Aboriginal AIDS Network (CAAN), and when someone refers to themselves as Aboriginal; otherwise, I use the term Indigenous.

1.3 Inspiration for the research

In the spring of 2011, I was put in contact with the Project Coordinator of the HIV/AIDS Labrador Project, which is housed at the Labrador Friendship Centre (LFC) in Happy Valley-Goose Bay (HV-GB), Labrador. She had heard about my interest and experience in the use of the arts in HIV/AIDS education with Indigenous youth and was interested in developing an arts-based strategy for the youth served by her program’s mandate. I advised her that I was a doctoral student and I was learning but I would be interested in partnering on such a research study. We decided to collaborate to develop, implement, and evaluate an arts-based HIV/AIDS education workshop for Indigenous

youth. We began a process of building relationships, seeking funding, and consulting with stakeholders in order to develop a program that would best suit the needs of the community.

1.4 Purpose of Study

The purpose of this study was to explore the use of the arts as a strategy for HIV/AIDS education and prevention with Indigenous youth. As we began this project, our aims were to develop, implement, and evaluate an arts-based strategy for Indigenous youth in Happy Valley - Goose Bay, Labrador in order to both increase the depth of understanding of arts-based HIV/AIDS education programs and the experiences of people participating in an arts-based HIV/AIDS education program.

In addition to it being a need identified from within the community, arts-based HIV/AIDS prevention and education initiatives have become increasingly popular strategies with a number of populations including Indigenous youth. However, there is a dearth of research exploring their development, use, evaluation, and reception (Boydell et al., 2012; Daykin et al., 2008). This study addresses these gaps in the literature.

1.5 Locating the researcher

Iseke and Moore (2011) write, “a respectful way to work in a community is to locate oneself within the research process and in relation to the community” (p. 21). This is particularly the case when working in an Indigenous community, when engaging in community-based research, and also when one is an “outsider” in every way to the community (Minkler, 2004). As noted, my connection with this community began when I was asked by the HIV/AIDS coordinator to partner in this research due to my previous

experience in the arts, Indigenous health, and HIV/AIDS education. At that point, I had never been to Labrador.

I am a non-Indigenous, white, second-generation Canadian woman who grew up in southern Ontario. I have always been committed to issues of social justice, culture, and health. I believe that there are many ways of knowing and many ways of doing things. As an ally to Indigenous Peoples, I have always been interested in challenging dominant and oppressive research structures and creating more space for decolonizing research in academia. Additionally, I see an opportunity to use academic training and resources to work towards improving the health of Indigenous people with an agenda driven by Indigenous communities.

I have worked cross-culturally in the field of HIV/AIDS with Indigenous youth in Canada and with youth in Ghana and Thailand. These experiences have illustrated to me how important it is for HIV prevention messages to come from within a cultural community. These experiences also demonstrated to me the need for innovative and creative strategies for HIV/AIDS prevention and education, for reducing stigma, and for improving quality of life for people living with HIV/AIDS. Additionally, I have been actively involved in the arts all of my life. I obtained a master's degree in Ethnomusicology in which I studied the use of arts-based strategies for HIV/AIDS education for a variety of populations and focused on the use of hip hop as a strategy for HIV/AIDS education with Indigenous youth. I think the arts play an important role in all cultures, including Indigenous cultures, as well as for many Indigenous people. I believe

the role of the arts and their relationship to health is often underappreciated and misunderstood.

Throughout my doctoral research, I have been very aware of my position as an outsider, both as a non-Indigenous woman and as someone who had never been to Labrador prior to this research. As such, it has been important to me to spend as much time as possible listening and learning in Happy Valley-Goose Bay, the community in which the research was conducted. As well, I felt it was important to continue to let people know throughout the research process that I was a researcher-in-training, a student, that I was working towards a graduate degree through this research, and that I had obligations such as course work, comprehensive exams, and ethics approvals that would shape the timeline of my involvement.

I was also aware that I brought culturally-based lenses to the research that shape the way I interact with and observe the world. Being cognizant that these lenses are culturally shaped and that there may be many different ontological standpoints in cross-cultural research was extremely important to me. Over the course of my doctoral studies, Two-Eyed Seeing gained popularity as a framework that celebrated multiple ways of knowing. Two-Eyed Seeing brings together Indigenous and western ontologies by using the strengths of both (Bartlett, Marshall, & Marshall, 2012; Iwama, Marshall, Marshall, & Bartlett, 2009; Martin, 2012). I found this framework very appealing for cross-cultural (or cross-ontological) research and considered how it may be applicable in this research project. Ultimately, as will be described below, I aimed to create a safe space for multiple

ways of knowing, welcoming both Indigenous and western ontologies throughout both the workshop and research process.

Additionally, due to these interests during my PhD studies, I took a graduate course called “When Worlds Meet: Nature/Culture and Ontological Conflicts,” taught by Dr. Blaser, to attempt to find the language to talk about ontological difference. I now realize that I wanted to find ways to talk about ontological difference outside of the academic setting, in everyday life. In order to continue exploring these ideas, I complemented this course by reading as much Indigenous literature as I could get my hands on. In addition to the academically oriented work of authors such as Linda Tuhiwai Smith (1999), Margaret Kovach (2009), and Shawn Wilson (2008), I was also greatly influenced by the writing of authors such as Thomas King (2008, 2012) and Richard Wagamese (2012, 2014).

My worldview and approach to Indigenous health research is also informed by the acknowledgement that we are living in a neocolonial era (Browne, Smye, & Varcoe, 2005). Indigenous peoples’ lives continue to be shaped by ongoing colonialization. In this way, research grounded in postcolonial theory can highlight how colonization continues to “shape health, healing, and access to health care” for Indigenous people (Browne, Smye, & Varcoe, 2005, p. 26). Additionally, research based in postcolonial theory, which is often oriented towards social change, can “draw critical attention to issues of partnership and voice in the research process, ... critique the colonizing potential of research, and in the process take steps to mitigate potentially detrimental consequences” (Browne, Smye, & Varcoe, 2005, p. 26). Likewise, my research interests and approaches

are also greatly influenced by and grounded in critical and indigenous inquiry. Denzin, Lincoln, and Smith (2008) define these terms in their *Handbook of Critical and Indigenous Methodologies*. Critical indigenous pedagogy is an approach to research that views all research as “political and moral” (Denzin, Lincoln, & Smith, 2008, p. 2). They suggest that critical indigenous pedagogy,

uses methods critically, for explicit social justice purposes. It values the transformative power of indigenous, subjugated knowledges. It values the pedagogical practices that produce these knowledges, and it seeks forms of praxis and inquiry that are emancipatory and empowering...such inquiry should meet multiple criteria. It must be ethical, performative, healing, transformative, decolonizing, and participatory. It must be committed to dialogue, community, self-determination, and cultural autonomy. It must meet people’s perceived needs. It must resist efforts to confine inquiry to a single paradigm or interpretive strategy. It must be unruly, disruptive, critical, and dedicated to the goals of justice and equity. (Denzin, Lincoln, & Smith, 2008, p. 2)

As indicated by this definition, I aim for my research approaches to be decolonizing, to address issues of colonization throughout the research. However, I realize that I come to this research through a colonial institution and have felt this tension in my research.¹ In terms of research, decolonizing strategies shift research being done

¹ For instance, as a graduate student pursuing research in Newfoundland and Labrador, I had to obtain approval for my research from the province’s research ethics board, whose policies may differ from Indigenous research review boards. This tension will be further discussed in the concluding chapter of my dissertation.

on Indigenous people to a research agenda driven by Indigenous people (Smith, 1999).

Martin (2012) states that

a decolonized approach to research requires that all stages of research critically reflect on *how* questions are asked, *why* they are being asked and by *whom*.

Through the process of reflecting on the entire research *process*, the purpose of research becomes more than just the production of new knowledge; it upholds the pedagogical, political, moral and ethical principles that resist oppression and contribute to strategies that reposition research to reflect the unique knowledge, beliefs, and values of Indigenous communities. Thus, it creates research that always “begins with the concerns of Indigenous people. It is assessed in terms of the benefits it creates for them” (Denzin & Lincoln, 2008, p.2). In doing so, it offers a means for Indigenous peoples to address the political and social conditions that perpetuate ill health, poverty, and lack of educational opportunities in their communities. (p. 30)

Fortier (2017) outlines some strategies for decolonizing research. He states decolonizing research strategies should recognize multiple ontologies, situate contemporary health issues within the context of settler colonialism, involve critical self-reflexivity of the researcher, and engage in longstanding relationship with Indigenous people and communities (Fortier, 2017). I have considered and integrated each of these strategies throughout my doctoral research: I have used a research approach that celebrates multiple ways of knowing; I have situated HIV and HIV prevention with Indigenous youth within the context of colonialism; I have been reflexive throughout the

research process, keeping a journal of my thoughts and research decisions; and I also spent as much time as possible in the community where the research was conducted and built relationships with the members of the community, research partners, and participants. In addition to these decolonizing research strategies, I have also used a community-based research (CBR) approach and an arts-based approach to HIV prevention. Both of these approaches are also linked to decolonizing research processes (Flicker et al., 2014). All of these decolonizing strategies will be discussed further in the following pages.

Informed by these perspectives, I have been very cognizant of my status as a non-Indigenous, white woman, and outsider to the community. I am also very aware that I am the author of this thesis, and as such, it is my voice and my framing that shapes this document and the presentation of others' experiences. Influenced by postcolonial, decolonizing, critical, and Indigenous approaches to research, I used qualitative content analysis and included lengthy quotations to support this analysis in order to stay close to the data and close to participants' own words. I also chose to use a community-based research approach, discussed in the next section, as it is congruent with the research approaches and principles I wished to follow, and ensured that I remained engaged with community members throughout the research, including the study framing, analysis, and results dissemination stages. Although I was cognizant, reflexive, and attentive to my role as a non-Indigenous academic-in-training throughout this research, I am also aware of the limitations of conducting this research within a western institution. These limitations will be discussed further in the concluding chapter. Additionally, although this program

development and evaluation is tailored to community needs and strengths, it is still set within a traditional western service delivery model. However, this research contributes to an ongoing shift to incorporate (and restore) culture and return control to Indigenous communities, working towards self-determination (FNIGC, 2018; Patterson, Jackson, & Edwards, 2006; Wallerstein & Duran, 2006).

1.6 Study Setting

Labrador is the mainland part of the province of Newfoundland and Labrador (NL) located on the east coast of Canada. It encompasses the traditional lands of three main groups of Indigenous Peoples in NL, the Inuit (Nunatsiavut²), Innu (Innu Nation³) and Southern Inuit (NunatuKavut⁴).

Happy Valley-Goose Bay is a town in the central part of Labrador on the coast of Lake Melville. It is the second largest community in Labrador. It serves as the medical services centre and transportation hub for many of the coastal and rural communities in Labrador. In 2016, Happy Valley-Goose Bay was home to approximately 6408 people, 2965 (46.3%) of which identified as Aboriginal on the 2016 Census (Statistics Canada, 2017). Members of all three Indigenous groups in Labrador, as well as many non-Indigenous people live in Happy Valley – Goose Bay. Approximately 6.3% of the

² Nunatsiavut is a “self-governing Inuit regional government.” “Nunatsiavut is the first of the Inuit regions in Canada to have achieved self-government” by including self-government provision in their land claim (Nunatsiavut Government, 2017). Their traditional lands cover much of the north coast of Labrador. HV-GB is not situated within their traditional lands.

³ The Innu Nation represents the Innu people living in Labrador. Currently, most Innu live in two communities in Labrador, Sheshatshiu and Natuashish. The Innu became recognized as a First Nation under Canada’s Indian Act in 2006 (Innu Nation). There are approximately 2200 Innu living in Labrador.

⁴ NunatuKavut represents the southern Inuit who live mostly in southern and central Labrador. There are approximately 6000 members of NunatuKavut living in Labrador (NunatuKavut, 2013).

population identified as First Nations, 31.2% of the population identified as Inuit, and 13.8% of the population identified as Métis⁵ (Statistics Canada, 2017). Approximately 99% of the population learned English as their first language (Statistics Canada, 2017). In relation to Indigenous languages, 0.6% of the population spoke an Inuit language (e.g. Inuktitut) as their first language and 0.7% spoke Innu-aimun as their first language (Statistics Canada, 2017). In 2016, approximately 765 people were between the ages of 10 and 19 (50% male) (Statistics Canada, 2017).

The political history of Indigenous Peoples in Newfoundland and Labrador has greatly differed from the political history of Indigenous Peoples in other provinces. Beginning in the 18th century, Moravian missionaries settled on the coasts of Labrador and did their “best to keep the Settlers and Inuit populations separate, which contributed to the rise of a specific ethnic consciousness on the part of the Settlers” (Grammond, 2014, p. 479). Additionally, when Newfoundland and Labrador joined Canada in 1949, there was no legal recognition of the Indigenous Peoples in the province (Gabel, Pace, & Ryan, 2016). The government developed a designated community⁶ system that allowed them to not engage in the politics of Indigeneity (Grammond, 2014). As late as 1982, there was still no legal recognition of the Indigenous Peoples living in NL (Grammond, 2014). Since 1982, Canada’s federal government has created bands and reserves for two Innu communities in Labrador and has signed a treaty with the Labrador Inuit Association (Grammond, 2014). Additionally, there has been progress made with regard

⁵ Members of NunatuKavut were at one time referred to as Métis, but this term is outdated. Members of NunatuKavut refer to themselves as Southern Inuit.

⁶ Designated communities were located only in the northern part of Labrador.

to the claims of the Labrador Métis Nation, which now has some formal recognition by the courts (Grammond, 2014). Each Indigenous group in Labrador has “secured different types of status, rights, and benefits” with the colonial governments (Grammond, 2014, p. 497). Currently, the Inuit region of Nunatsiavut is the first Inuit region to have obtained self-governance. Grammond (2014) argues that the ways in which Indigenous Peoples in Labrador argued for recognition reinforced a hierarchical system of Indigeneity within the province. Likewise, Brunger and Bull (2011) argue the three governing organizations of Indigenous Peoples in Labrador “must vie for access to federal program and project monies. As a result, resources and power are unequally distributed among all three, as well as within each of them” (p. 130).

Similar to Indigenous Peoples in other regions of Canada, in the last 60 years, Indigenous Peoples in Labrador have experienced forced settlement and forced relocation resulting in loss of land, culture and lifestyle as nomadic cultures were transformed in to sedentary communities (Brunger & Bull, 2011; Cunsolo Willox, 2012). Due to colonial policies, Indigenous children in Labrador were removed from families and sent to residential schools “resulting in widespread spiritual and cultural assimilation, language erosion, discrimination, and marginalization” (Cunsolo Willox et al., 2012, p.540). Additionally, as a result of colonization, they have faced physical, emotional, and sexual abuse; “the extermination of dog teams; an almost complete destruction of land-based economies such as the seal skin industry; and a change to a wage-based economy, with resulting changes in socio-cultural roles and responsibilities” (Cunsolo Willox, 2012, p. 51). Additionally, similar to other Indigenous Peoples, they have experienced a history of

research *on* their people, rather than *with* their people. This history has made many Indigenous Peoples, including in Labrador, skeptical of research and researchers from outside their communities. For instance, Brunger and Bull (2011), who were working with NunatuKavut to develop a research review process for their people, described feelings of resistance to research by Indigenous Peoples including in Labrador arising from ongoing colonization, lack of consultation and involvement in the research process, lack of access to data and findings, and lack of timely benefit from research. They state,

Indigenous peoples have endured various inquests and inquiries about their health, education, culture, and traditions. Such efforts have primarily been conducted under government and academic programs and have rarely included members of the Aboriginal communities in the decision-making process. Over time, resistance has developed among Aboriginal peoples (e.g., Humphrey 2007). Perceived exploitation in research, research fatigue, and past and present relationships with governments have influenced the ways the key stakeholders understand ethics and research. At the time of this writing, the [people of] NunatuKavut are strongly opposed to the proposed hydroelectric project at Muskrat Falls on Labrador's Churchill River. It is clear to us, from our conversations with community members, that such resistance is an effect, and not merely a cause, of the way in which academic and government research is perceived. Their words—"We are sick of being studied to death"—echo the work of Linda Tuhiwai Smith (1999), a Maori scholar who emphasises the need for decolonisation in all aspects of research (p. 131)

Again, being aware of the impacts of colonization and the history of research *on* Indigenous Peoples, I adopted a community-based research approach, which can help to mitigate power imbalances and emphasizes moving knowledge (creation) to action.

1.7 Community-Based Research

Moving forward with this research project, I adopted a community-based research approach. The term community-based research has been used to describe a number of approaches to research that focus on “participation, research, and action” (Minkler, 2005, p. ii3). In general, community-based research is “an orientation to research that focuses on relationships between academic and community partners, with principles of colearning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts” (Wallerstein & Duran, 2006, p. 312). There are two main traditions of CBR, which are referred to as the northern and southern traditions. The northern tradition, linked with the work of Kurt Lewin, comes out of social science and action research and is concerned with “how to solve practical problems within organizations through a research cycle of planning, action, and an investigation of the results of the action” (Kleiner, Kersetter, & Green, 2012, p. 2).

The southern tradition is linked to liberation pedagogy and is often associated with the work of Paulo Freire (Minkler, 2005; Tiessen & Beaulac, 2013). In the southern tradition, CBR is “a direct counter to the often ‘colonizing’ nature of research to which oppressed communities were subjected, with feminist and postcolonialist scholars adding further conceptual richness” (Minkler, 2005, p. ii4). The southern tradition is grounded in

ideas of social justice, decolonization, and emancipation (Wallerstein & Duran, 2008). Although emerging from different philosophical standpoints, both the northern and southern tradition of CBR are concerned with action-oriented research that involves the participation of community and is aimed at creating social change (Kleiner, Kersetter, & Green, 2012; Wallerstein & Duran, 2008).

CBR approaches challenge “traditional” academic approaches to research that may view academics as experts and participants as vessels for data extraction. In stark contrast to the traditional roles of the researcher and researched, CBR views participants as experts in their experiences and as knowledge creators or producers (Israel, Schulz, Parker, & Becker, 1998). Similarly, Flicker and colleagues (2008) state that “CBR is not a method but an approach to research that emphasizes the importance of collaboration, participation and social justice agendas over positivist notions of objectivity and the idea that science is apolitical” (p.2). Additionally, Minkler (2005) states that “[CBR] embodies a deep commitment to what Tervalon and Murray-Garcia have called cultural humility” (Minkler, 2005, p. ii4). She suggests that “although we can never become truly competent in another’s culture, we can demonstrate a ‘lifelong commitment to self evaluation and self-critique,’ to redress power imbalances and ‘develop and maintain mutually respectful and dynamic partnerships with communities’” (Tervalon & Murray-Garcia, 1998, as cited in Minkler, 2005, p. ii4–ii5).

A CBR approach appealed to me for many reasons. It seemed fitting as not only was I approached by someone with a research problem within her community, I was also aware of the negative impacts much research has had on Indigenous people and

communities throughout history. For instance, research has been used to justify colonial policies and practices with an agenda of controlling and defining Indigenous peoples usually to benefit colonial powers (Browne & Varcoe, 2006; Ermine, Sinclair, & Jeffery, 2004; King, 2012; Kovach, 2009; Tuiwai Smith, 1999). Additionally, there is an ongoing history of “outsiders” doing research *on* Indigenous people around the world. There are still many cases where data is collected from Indigenous people, or from Indigenous lands, without appropriate consultation and consent, findings are not reported back to the communities, and often the research does not result in necessary (or promised) change (Kovach, 2009; Smith, 1999). (As I have heard many people say, “We do not need another study to tell us our water is not clean!”)

Using a CBR approach can help to mitigate the power imbalance in research involving Indigenous people and contribute to a decolonizing research approach. In fact, a CBR approach is often adopted in Indigenous health research (Nowgesic, 2015). In Canada, Chapter 9 of the Tri-Council Policy Statement 2 (TCPS 2) on research involving Indigenous Peoples suggests that CBR is an appropriate approach to research with Indigenous people (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council, & Social Sciences and Humanities Research Council, 2014). CIHR’s guidelines, on which this policy is based, state,

Historically, Aboriginal communities have been the subject of much research by “outsiders”. This colonial approach to research in Aboriginal communities should give way to an understanding that Aboriginal people have an inherent right to be agents of research in contrast to mere passive subjects when the research topic

involves their community or culture. One important means of respecting this right to participate is to actively enable community involvement in a research project. (CIHR, 2013)

A CBR approach involves the participation of participants, community members, and stakeholders in the research process, which allows for shared decision-making and power over the research. Ethical research practices with Indigenous communities also include building respectful relationships. Building respectful relationships with community is also a tenet of a CBR approach (Israel et al., 2008).

CBR is also congruent with the principles of OCAP®⁷ (ownership, control, access and possession over research), which are ethical tenets for doing research with First Nations Peoples in Canada. This term describes “a set of standards that establish how First Nations data should be collected, protected, used, or shared” (FNIGC, 2018). However, this term appears in the Tri-council policy statement outlining ethical approaches to research with all Indigenous people in Canada. As well, the NunatuKavut Research Advisory Council uses this term in their guidelines for researchers and requests that researchers seeking their approval identify how their proposed research protocols respect these principles (Community Council Research Advisory Committee, 2013).

Additionally, knowledge translation and capacity building are inherently part of the CBR process. This research approach prioritizes putting knowledge gained into

⁷ OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). www.FNIGC.ca/OCAP.

practice through an iterative process of action and critical reflection (Green & Thorogood, 2013; Masching, Archibald, & Jackson, 2009; Minkler, 2004).

All of these principles of CBR and ethical research with Indigenous people were carefully considered throughout design and implementation of this research project. For instance, this research project was guided by an Advisory Committee made up of stakeholders in the research, including Elders, youth, and health professionals. I met with these stakeholders throughout the research process. We discussed and made plans for how data would be “owned” and “used,” and discussed the development of the workshop and research questions. These issues will be discussed further in the sections detailing the development of the workshop.

1.8 Partnership Building

The Labrador Friendship Centre (LFC) opened its doors in 1974 in Happy Valley-Goose Bay. The Centre provides a number of services and programs for Indigenous people throughout Labrador (Labrador Friendship Centre, 2014). The HIV/AIDS Labrador Project is housed at the LFC and has been operating since 2000. Arising out of a needs assessment report (Labrador Friendship Centre, 2014; Ratnam & Myers, 2000), the Project is dedicated to providing HIV/AIDS and sexually transmitted and blood-borne infection (STBBI) education to a variety of populations including youth, inmates, and the general population throughout Labrador (Labrador Friendship Centre, 2014; Ratnam & Myers, 2000). Much of their work involves leading educational sessions at schools and hosting community events. The Project is led by the HIV/AIDS coordinator and is guided by an Advisory Committee that is made up of community stakeholders including Elders,

youth, representation from the regional health authority (Labrador-Grenfell Health), and Indigenous governments (including NunatuKavut and Nunatsiavut) (Labrador Friendship Centre, 2014).

Letters of support for this research study were received from the executive director of the Labrador Friendship Centre and the program coordinator of the HIV/AIDS Labrador Project. These letters were submitted with funding applications and with the ethics applications for this study.

Following a CBR approach, I spent as much time as possible in HV-GB in order to better understand the local context, and to build relationships with my community partners, the Advisory Committee, and other stakeholders including youth in the community (Appendix A). My early trips to HV-GB involved meetings with the HIV/AIDS coordinator, executive director of the LFC, health workers, members of the Advisory Committee, research coordinators for Nunatsiavut, NunatuKavut, members of the health authority, and staff at the health clinic for the Innu Nation. As well, I participated in a provincial workshop on Aboriginal Health Research Ethics (Sept 2011), health fairs, and other community events. I also volunteered with the Labrador Creative Arts Festival, Canada's longest running children's festival (2013, 2014 and 2015) and I served on the board for the festival in 2015. This festival gave me the opportunity to connect with youth from all over Labrador and also allowed me to better understand the context of the arts in Labrador.

1.9 Research questions

Through discussions and consultations with the coordinator of the HIV/AIDS Labrador Project and its Advisory Committee, we developed several research questions. First, we wanted to know if knowledge and attitudes regarding HIV/AIDS would, in fact, change after participation in an arts-based workshop. My research partners were particularly interested in collecting data on the effectiveness of the workshop as this data could be useful to them in their reports to funders as well as in future funding applications. Second, we were interested in understanding the perceptions and experience of the participants in an arts-based HIV/AIDS education workshop. As will be discussed in the literature review, in recent years, there has been increasing interest in the use of the arts in HIV/AIDS prevention with Indigenous youth due to their perceived ability to be engaging and their potential as educational, culturally appropriate, and decolonizing strategies. However, there is a dearth of research exploring how participants perceive the use of the arts in such contexts and whether participants do indeed experience arts-based strategies as engaging, educational, culturally appropriate, and decolonizing. Hence, the initial research questions this study sought to answer were:

- 1) How do self-identifying Indigenous youth experience an arts-based HIV/AIDS education workshop?
- 2) Does participating in an arts-based HIV/AIDS education workshop result in a change in knowledge and attitudes among the participants?

Due to the iterative nature of CBR studies, things change. Although they initially were not included as a participant group, several Elders were part of the workshop and asked to

more actively participate. Accordingly, we revised our research questions to include a third,

- 3) How do self-identifying Indigenous Elders experience an arts-based HIV/AIDS education workshop for Indigenous youth?

1.10 Methodological Framework

A methodological framework assumes a set of underlying theoretical principles about the nature of knowledge and the ways in which things can become known. A methodological framework should also correspond to the research questions being asked. In this case, given the participatory principles and explicit social change-oriented values inherent within decolonizing and CBR approaches, with a research focus on program implementation and outcomes, I adopted a mixed methods design grounded in a pragmatic approach, as the research questions sought to comprehensively explore the use, utility, and experience of an arts-based HIV/AIDS education strategy for Indigenous youth. Pragmatism as an approach in research refers to a paradigm in which researchers “use all approaches available to understand the problem” (Creswell, 2014, p. 10). It allows for the use of multiple ways of knowing, multiple types of data, and multiple strategies for data collection.

Mixed methods research designs are congruent with a pragmatic research paradigm. Mixed methods research utilizes both qualitative and quantitative data in order to provide a comprehensive understanding of a research problem as the use of multiple types of data provides a deeper understanding than would be achieved through qualitative or quantitative research methods alone (Creswell, 2014; Tashakkori & Teddlie, 1998).

This approach is also congruent with the principles of two-eyed seeing. As stated, two-eyed seeing is an approach to research developed by Mi'kmaw Elders Albert and Murdena Marshall. A two-eyed seeing approach makes space for and celebrates multiple ways of knowing in research. Two-eyed seeing is also built on the understanding that knowledge is socially constructed and relational (Martin, 2012). While a primarily western lens was used in constructing the research questions, as this was the framing desired by my research partner, the community-based approach to the research allowed for social constructionist and Indigenous lenses to be applied to the research process, as well as the workshop development, process, and content. In this study, we used both quantitative and qualitative methods to provide an exploratory, descriptive evaluation of this arts-based HIV/AIDS education workshop. Data collection included semi-structured interviews with the workshop participants and a pretest and posttest design measuring knowledge and attitude change after the workshop.

1.11 Exploring participants' experiences

Qualitative methods were used to investigate the participants' (both youth and Elders) experiences at the workshop. These research questions, seeking to understand the experiences of youth and Elders, arise from the inductive, theoretical research approach of social constructivism. Within a social constructivist view, there is no objective reality. Rather, reality is socially constructed, produced by individuals, and situated in both time and place (Wilson & Clissett, 2011). Within a social constructivist framework, the researcher is aware that reality is subjective and that her presence will have an impact on the phenomenon she wishes to study. In fact, within this paradigm, knowledge creation is

hermeneutical and dialectical (Guba & Lincoln, 1994; Lincoln, Lynham, & Guba, 2011). It is the “interaction of the researcher and participant” that “creates knowledge and understanding” (Wilson & Clissett, 2011, p. 678).

The focus of social constructivist research is on the meaning and understanding of a phenomenon as it “seeks to generate the most sophisticated description or explanation of a particular setting as a result of an interactive process between the researcher and participant, many of whom are likely to hold differing perspectives about individual situations” (Wilson & Clissett, 2011, p. 678). Hence, this was an appropriate paradigm to work from as this research question seeks to explore and describe the realities of the Indigenous youth and Elders participating in this arts-based HIV/AIDS education workshop.

1.12 Evaluating knowledge and attitude change

Quantitative and qualitative methods were used to evaluate whether knowledge and attitudes about HIV/AIDS changed after participating in the workshop. A pretest/posttest design was used to measure knowledge and attitude change after the workshop. Qualitative methods were used to further explore youth’s perceptions of their HIV/AIDS knowledge and attitude changes. Using a combination of research methods and approaches allows for a comprehensive in-depth understanding of the phenomenon being researched (Creswell & Creswell, 2017; Mertens, 2011; Mertens, 2014; Tashakkori & Teddlie, 1998; Tashakkori & Teddlie, 2010).

1.13 Ethics

The Newfoundland and Labrador provincial Health Research Ethics Board (NL HREB) (#14 147) and NunatuKavut's Research Advisory Committee provided ethics approval for this study. I also met with the research coordinator for the Nunatsiavut Government during the early development of the research project and information about this study was given to Nunatsiavut throughout the research process. Nunatsiavut's research review board only reviews research conducted on Nunatsiavut lands. The Innu Nation had no official research ethics process at the time of this research. Letters of support for this research collaboration were received from the coordinator of the HIV/AIDS Labrador Project, as well as the executive director of the Labrador Friendship Centre. Working in collaboration with these partners and with the HIV/AIDS Labrador Project's Advisory Committee helped to ensure that appropriate ethical measures were considered throughout the project for doing research within their community and with the people they serve.

1.14 Rationale for the study: A review of the literature

In Canada, Indigenous people face a disproportionate burden of disease including overrepresentation in rates of HIV infection (Adelson, 2005; Gracey & King, 2009; PHAC, 2014). Indigenous people account for 4.3 percent of Canada's population, and yet, in 2014 accounted for approximately 10.8 percent of all new HIV infections in Canada (PHAC, 2015a). The Public Health Agency of Canada (PHAC) estimates that HIV infection rates are more than three times higher within Canada's Indigenous population than for non-Indigenous residents of Canada. In addition to being disproportionately affected by this pandemic, PHAC estimates that Indigenous people

tend to contract HIV at a younger age (ten years younger) than the general population (PHAC, 2014), often receive treatment at later stages of the disease (Nowgesic, 2015). Indigenous women are more greatly affected by HIV than are Indigenous men (PHAC, 2014). The primary methods of transmission of HIV among Indigenous people are through heterosexual sex with an infected partner (40 percent of new infections in 2014) and through intravenous drug use with contaminated equipment (45 percent of new infections in 2014) (PHAC, 2014). In Canada, Indigenous youth have a higher risk of contracting HIV than do their non-Indigenous counterparts (PHAC, 2014). Indigenous youth, in particular, “are more likely to be diagnosed late, more likely to have an earlier onset of acute illness, less likely to received optimal medical care, and have shorter survival rates” (Smillie-Adjarkwa et al., 2013).

Indigenous people are overrepresented in the HIV pandemic for a variety of reasons. The determinants of Indigenous health are biologically, socially, politically, and environmentally driven (Adelson, 2005; Greenwood, De Leeuw, Lindsay, & Reading, 2015; Loppie Reading & Wien, 2009; Richmond & Ross, 2009; Smylie, 2013). As a result, health disparities between Indigenous and non-Indigenous populations are fuelled by factors such as the ongoing legacy of colonialism which is a determinant of Indigenous Peoples’ health (Adelson, 2005; Gracey & King, 2009; Loppie Reading & Wien, 2009). For example, the ongoing legacy of colonization has resulted in poverty, racism, and intergenerational trauma and the loss of autonomy, self-governance, traditional ways of life and lands for many Indigenous people. These factors have negatively impacted the health and wellbeing of Indigenous people by contributing to

poorer health outcomes including higher rates of HIV infection (Smillie-Adjarkwa et al., 2013). Likewise, PHAC (2014) recognises that vulnerability to HIV infection among Canada's Indigenous people is linked to many determinants of health including poverty, unstable housing and homelessness, poor mental health and addictions, traumatic childhood experiences, racism, the multi-generational effects of colonialism, and the residential school system.

The prevalence and incidence of HIV are low in Newfoundland and Labrador compared to other regions of Canada (2.5 cases per 100000 in NL in 2015 versus 5.8 cases per 100000 as a national average (PHAC, 2015a). However, it is difficult to obtain estimates of prevalence and incidence of HIV in Labrador specifically, as well as within the Indigenous population, due to data collection and reporting methods.⁸ Additionally, PHAC estimates that 20 percent of people living with HIV in Canada are not aware of their status (PHAC, 2015b). Nevertheless, a needs assessment in Labrador identified high rates of other STBBIs such as gonorrhea and chlamydia and high rates of teen pregnancy as indicators that HIV infection would spread quickly if introduced into the population (Ratnam & Myers, 2000). The Labrador HIV/AIDS Surveillance Study identified a need for an HIV/AIDS prevention program targeting Indigenous youth (Labrador Friendship Centre 2012; Ratnam & Myers, 2000). Since this time the Labrador Friendship Centre has supported the HIV/AIDS Labrador Project.

⁸ The Newfoundland and Labrador provincial government has not provided information regarding AIDS cases or related ethnicity data to PHAC since 2005 (PHAC, 2014).

1.14.1 HIV prevention models

There are many different models for addressing HIV prevention. Some models that focus on individual behaviour change include the information motivation behavioural skills model (IMB), theory of planned action (TPA), and the health belief model (HBM), social marketing, sexual script theory, and social learning/cognitive theory (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013; Boutin-Foster et al., 2010; Lemieux, Fisher, & Pratto, 2008). These models focus on addressing individual level factors such as knowledge, attitudes, and behaviours to reduce rates of HIV infection. In these models, improving knowledge and attitudes are linked through a variety of mechanisms to reducing behaviours related to HIV transmission. However, studies have shown little correlation between simply improving knowledge and reducing HIV-transmitting behaviours for a variety of reasons, including the lack of acknowledgement for contextual, social, and structural factors (Kasen, Vaughn, & Walter, 1992; Mitchell et al., 2002; Sriranganathan et al., 2012). On the other hand, social ecological models of HIV prevention account for the “complex associations between the social (e.g. social networks) and structural (e.g. access to care) factors, individual practices, the physical environment and health” (Baral et al., 2013, p. 2). Baral and colleagues (2013) state,

The social ecological model contextualizes individuals’ behaviors using dimensions including intrapersonal (e.g. knowledge, attitudes, behavior), interpersonal/network (social networks, social support), community (e.g. relationships among organizations/ institutions), and public policy (e.g. local, state, national laws) to provide a framework for describing the interactions

between these levels...Ecological models focusing on intrapersonal factors have been widely used in the design of effective interventions aimed at modifying individual behaviors. (p. 2)

The social ecological model of HIV prevention is implicit in the HIV prevention workshop that was developed through the course of this research. Improving intrapersonal factors such as HIV/AIDS-related knowledge and attitudes are only one part of HIV/AIDS prevention. Social and structural factors must also be addressed in order to curb HIV infection rates (Auerbach, Parkhurst, & Cáceres, 2011; Baral et al., 2013). The workshop developed in collaboration with my research partners addressed intrapersonal factors that are part of HIV prevention (e.g., knowledge and attitudes), as well as social factors (i.e., addressing aspects of colonization and their impact on Indigenous health) and using culturally appropriate and decolonizing methods of engagement.

1.14.2 Indigenous HIV prevention

Some researchers suggest that traditional public health approaches such as campaigns aimed at individual behaviour change, basic knowledge-based campaigns, or ABC (abstinence, be faithful, condomize) campaigns are not adequate for addressing HIV/AIDS within Indigenous populations, as they do not account for the unique factors, including systemic factors (such as the impact of colonialism) that increase the risk of transmission and determine health for Indigenous people (Flicker et al., 2013; Flicker et al., 2014; Larkin et al., 2007). Innovative health promotion strategies that address the

determinants of Indigenous health and factors that increase the risk of HIV infections must be developed in order to curb infection rates (Flicker, 2013).

Effective HIV prevention strategies must consider and address the factors that make Indigenous people vulnerable to contracting the disease in the first place (Aguilera & Plasencia, 2005; Flicker et al., 2013). Larkin and colleagues (2007) suggest that “a response to the HIV/AIDS epidemic in Indigenous communities must begin with an understanding of the unique social, cultural and economic issues facing Aboriginal people” (p. 181). They found that Indigenous youth participating in their study “identified poverty, colonialism and other structural inequities as precipitating factors of risk” (Larkin et al., 2007, p. 181). Ultimately, prevention strategies need to be decolonizing as they aim to address colonialism, challenge behaviours, attitudes, and beliefs that propagate colonialism, as well as challenge the “institutional manifestations of colonialism” (Flicker et al., 2013, p. 161).

In a scoping review of HIV prevention with Indigenous youth, Ricci and colleagues (2009) identified characteristics of successful HIV prevention programming deemed to be “Wise Practices”⁹. One of the characteristics identified was the use of arts-based approaches (Ricci et al., 2009).

1.14.3 Arts-based HIV prevention with Indigenous youth

Health promotion is defined by the World Health Organization (WHO) (2018a) as “the process of enabling people to increase control over, and to improve, their health. It

⁹ The term “Wise Practice” has been adopted by some in this field including the Canadian Aboriginal AIDS Network as they feel this term is more culturally relevant than “best, good, or promising practices. The premise is that wisdom is knowledge put to use” (Barlow et al., 2008).

moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions.” Often considered an aspect of health promotion, the WHO (2018b) defines health education as “any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge or influencing their attitudes.” In recent years, arts-based initiatives have emerged as promising strategies for health promotion and health education with a variety of populations (Boydell et al., 2012). The arts, including painting, music, poetry, and theatre, have been used in health education initiatives such as learning about stroke, hand hygiene, heart disease, chronic pain, tobacco use, and sexual health, with target audiences including children, youth, adults, men, and women, all around the world (Boydell et al., 2012; Fanian et al., 2015; Williams & Noble, 2008).

Arts-based initiatives have also been used to address many issues around HIV including infection, stigma, drug use, and sexual health with a variety of marginalized youth including Indigenous youth (for Indigenous youth see Fanian et al., 2015; Flicker et al., 2012, Mikhailovich & Arabena, 2005, Lys et al., 2016, Lys, Logie, & Okumu, 2018; Ricci et al., 2009; for African American and Hispanic youth see Boutin-Foster et al., 2010, Lemieux et al., 2008; Stephens et al., 2000; Stokes & Gant 2002; Turner-Musa et al., 2008). In Canada, Lys and colleagues (2016) created an HIV prevention and leadership development program for Indigenous girls in the Northwest Territories using the arts. They found that young women aged 13-17 participating in their arts-based program, Fostering Open eXpression among Youth (FOXY), increased their knowledge

of STBBIs including HIV/AIDS, increased safer sex self efficacy, and increased resilience (Lys, Logie, & Okumu, 2018).

Flicker and colleagues developed a multi-site arts-based HIV/AIDS education and leadership development initiative, Taking Action and Taking Action II, for Indigenous youth (Flicker et al., 2012; Flicker et al., 2013; Flicker et al., 2014; Wilson et al., 2016). In Taking Action, Indigenous youth in six communities across Canada engaged in arts-based workshops (including hip hop, painting, theatre, video-making, graffiti, carving, and photography). The youth participants in their research reported finding the use of the arts to be “fun, participatory, and empowering” (Flicker et al., 2014). Additionally, their findings suggested, similar to the findings of others, that arts-based approaches can also be used as decolonizing strategies that empower their participants within a research setting (Castleden et al., 2008; Flicker et al., 2014; Prentice, 2015). Arts-based approaches can be empowering as participants may develop an increased sense of control and autonomy. Decolonizing arts-based approaches may be empowering as they

aim to create a more equal relationship between researchers and participants, in which the contents of the research (product) and its interpretation (process) belong to the participant and his or her community...art is not only a vehicle for conveying a message (product), but also a transformative medium for engaging with power structures, cultural values, and identity development (process).

(Flicker et al., 2014, p.28)

In addition to research on HIV prevention initiatives, many programs are using the arts to engage youth, to increase their levels of participation. For instance, Chee

Mamuk (2009) published “A Guide to Wise Practices for HIV/AIDS Education and Prevention programs” in which they lay out some basic points to consider when developing an arts-based initiative such as community readiness and offer examples of successful projects including a participatory filmmaking project for Indigenous youth. Additionally, the Canadian website, *Youth, the Arts, HIV and AIDS* (YAHAnet.org) showcases various types of art-based projects created by youth, including Indigenous youth, promoting HIV awareness and education.

1.14.4 Lack of evaluation of arts-based HIV/AIDS prevention

While arts-based interventions are becoming increasingly popular, evaluation of the effects of arts-based health promotion on youth is still in its infancy (Daykin et al., 2008). There continues to be a lack of research exploring and examining how these interventions are developed and implemented, and how they are experienced by the participants and program implementers. A better understanding of how arts-based HIV/AIDS prevention initiatives are experienced by participants may help to evaluate the intervention, allow for the voices of the participants to be heard, and help program designers create meaningful interventions in the future. As stated, this dissertation addresses this gap in the literature by providing a comprehensive assessment of an arts-based HIV/AIDS education initiative for Indigenous youth.

1.15 Developing an arts-based HIV/AIDS prevention workshop

The development of the workshop that is the subject of my dissertation was guided by the HIV/AIDS program coordinator, the HIV/AIDS Project Advisory

Committee, discussions with community youth and other stakeholders, and a review of the literature.

As previously discussed, the literature identifies a number of “Wise Practices” for HIV/AIDS education and prevention with Indigenous youth in Canada. The Canadian Aboriginal AIDS Network published a National Aboriginal Youth Strategy on HIV/AIDS in Canada (2010) as well as a report on HIV prevention messaging for Indigenous youth (2004). Additionally, as indicated, Chee Mamuk (2009) published a “Wise Practices” guide to HIV/AIDS prevention for Indigenous youth. The scoping review by Ricci and colleagues on HIV prevention with Indigenous youth identifies overlapping “Wise Practices” which include:

- (a) reaching youth at a younger age;
- (b) adopting peer education approaches;
- (c) leveraging partnerships;
- (d) addressing colonial impacts in HIV prevention efforts;
- (e) attending to diversity;
- (f) addressing stigma;
- (g) revising current educational practices;
- (h) adopting a harm reduction approach;
- (i) identifying testing as a potential point of prevention intervention;
- (j) incorporating arts-based approaches into prevention initiatives;
- (k) adopting culturally sensitive/decolonizing approaches to research conducted in partnership with Indigenous communities. (Ricci et al., 2009, p. 25)

In addition to these “Wise Practices,” the literature on HIV/AIDS prevention with Indigenous youth also suggests that “health promotion programs and practices are more effective when created from knowledge provided by Aboriginal youth themselves” (Banister & Begoray, 2006, p. 169) and that “information-based health education” is less effective than more participatory approaches to HIV prevention (Campbell & MacPhail, 2002, as cited in Flicker et al., 2014, p. 9).

Arts-based initiatives have emerged as engaging, empowering, and promising strategies for HIV/AIDS education and prevention with Indigenous youth. Flicker et al. (2014) argue that art-based approaches can also be used as a decolonizing strategy within research. Additionally, Flicker and colleagues (2013) found that “connecting youth with one another, as well as Aboriginal mentors, teachers, and artists may in itself be a form of decolonization and reclamation” (p. 17). Based on these recommendations, this arts-based workshop aimed to be participatory, strengths-based, decolonizing, educational, and engaging.

1.15.1 Choosing a study setting

Due to feasibility, expense, and population, the workshop was held in Happy Valley-Goose Bay, Labrador. Happy Valley-Goose Bay is a town in eastern Labrador, and is home to approximately 6500 people. The town serves as a transportation hub between the coastal communities of Labrador and the rest of the province. The town also hosts medical facilities that serve these communities. The HIV/AIDS Labrador Project is housed at the Labrador Friendship Centre located in Happy Valley-Goose Bay. An additional reason that we decided to hold the workshop in Happy Valley-Goose Bay was

that members of all three Indigenous groups would be able to participate in the workshop as the town is home to members of all three communities and is not part of the lands recognized as belonging to any one group as is the case in other regions of Labrador.¹⁰

1.15.2 Choosing a genre of arts

Due to the iterative nature of CBR and the desire to have youth input into the design of the workshop, we did not plan at the outset to do a filmmaking workshop. In my preparations for this research project, I had included a cursory overview of multiple genres of art used in HIV/AIDS prevention and education. However, shortly before the workshop was implemented, we conducted an informal survey through the coordinators of several local youth groups in order to find out what art forms community youth were interested in. This survey included genres such as painting, drumming, song, photography, carving, and filmmaking and asked youth to identify what type of art they were most interested in. Since the number one choice by the surveyed youth was filmmaking, we developed a participatory filmmaking and HIV/AIDS prevention workshop for youth.

There are many different ways to use film and filmmaking both in research and in a workshop. Some ways of using filmmaking are less participatory than others. For instance, having professional videographers create a community documentary may not give community members creative control over the production. Designing the program to

¹⁰ Beneficiaries of Nunatsiavut primarily reside in communities along the northern coast of Labrador. Beneficiaries of NunatuKavut primarily live in the towns on the southeastern Labrador coast. Members of the Innu Nation primarily live on the two Innu reserves, Sheshatshiu (Sheshatshiu Innu First Nation) and Natuashish (Mushuau Innu First Nation) (Brunger, Schiff, Morton-Ninomiya, & Bull, 2014). Happy Valley-Goose Bay is home to people from many different communities.

be participatory and group-oriented in nature was deliberate for many reasons. Keeping in line with “Wise Practices” identified in this area, we designed a participatory filmmaking workshop with the intention that filmmaking could be a decolonizing strategy that allowed for the voices of the participants to be heard. As well, this approach allowed the youth to learn filmmaking skills to “appropriate the means of production to produce new sorts of meaning” (Goldfarb, 2002, p.69). Additionally, our process was social, group/community-oriented, intergenerational, collaborative and creative, and aimed to put the control in participants’ hands.

1.15.3 HIV/AIDS educator

We invited an educator from Healing Our Nations (HON), an Indigenous HIV/AIDS education organization located on the east coast of Canada. The educator was an Indigenous woman. She facilitated three sessions with the participants: one with the middle school-aged youth, one with the high school-aged youth, and one with the Elders. The content of the sessions varied with the needs and ages of the participants.

1.15.4 Film facilitation

We hired three film facilitators including two Indigenous facilitators under the age of 30 to provide instruction on filmmaking. They also provided the necessary equipment and software for filmmaking. We decided to hire these facilitators as they had a proven record of their ability to work with groups, they had experience working with Indigenous youth and communities, they could facilitate the creation of a short film over a 3.5-day period, and they understood that the films were to be the youth’s creations.

1.15.5 Recruitment

Most recruitment was done by word-of-mouth. The recruitment poster was circulated on a community notices listserv, was posted around town and on Facebook, and was circulated by community contacts such as youth group leaders and other interested individuals (see Appendix B). Based on interest expressed in the community, we aimed to recruit youth ages eleven to twenty-six.

1.15.6 Informed Consent and Assent

Informed consent was obtained from each youth's parent or guardian prior to the youth's participation in the research project (Appendix C). Informed assent was given by each youth participant prior to participation in the research. Informed consent was given by each Elder prior to participation in the research. Ongoing informed consent was sought throughout the research process. I continued to check in with participants (and guardians, as required) at various points to confirm that they were comfortable with consenting to participate in the research and could withdraw at any time (i.e. during the workshop, at their interviews, and at the community film debut). I also continued to check with participants (and guardians, as required) about the use of their films for my research. I, like other researchers who use the arts (e.g. see Gubrium, Hill, & Flicker, 2014), felt that participants could not fully consent to the use of their films for research prior to their films being made, so we discussed the purpose, intention, and potential audience of the films, as well as ownership of the films before the films were made. Additionally, prior to the films being made we discussed the limitations regarding anonymity and confidentiality related to appearing and being credited in the film so that

participants could choose how they participated accordingly (i.e. if they wanted to be “on screen”). I also confirmed their consent for the films to be used after they were made, and I continued to check in about their consent for the use of their films in my research throughout the research process (for instance, I asked again at their interviews and at the community debut). Additionally, it was clearly indicated that the films were owned by the people who created them. It was up the films’ owners to decide what to do with the films when they were completed and that there had to be group consensus if the film was to be hosted online.

1.15.7 Participants

Eleven youth ages eleven to seventeen participated in the workshop. Three of the youth participants identified as male and the remaining eight youth participants identified as female. All participants self-identified as Indigenous.

1.15.8 Serendipitous participants

As part of a decolonizing approach, we invited Elders to participate in the workshop (Flicker et al., 2015; Hampton, McKay-McNabb, Jeffery, & McWatters, 2007). An Elder on the HIV/AIDS Labrador Project Advisory Committee invited several Elders he knew in the community to attend the workshop on the opening evening. He invited Elders from each of the Indigenous groups living in Labrador. He asked the Elders to open the workshop, and to lead us in ceremony and in a ‘good way’. Additionally, he asked if a couple of Elders could be present throughout the workshop. Beyond this, the Elders’ roles were intentionally flexible. Five Elders, members of NunatuKavut, Nunatsiavut, and the Innu Nation, attended on the first night. They opened the workshop

and one Elder lit a *kudlik*, a traditional Inuit oil-burning lamp carved of stone. Then, the youth were split into two groups. The middle school youth attended a workshop with the HIV/AIDS educator from HON, and the high school aged youth attended a workshop on the basics of filmmaking. During the first evening's activities, one Elder approached me to say the Elders were interested in attending the HIV/AIDS education workshop and later told me that they too would like to make a film. In the end, these five Elders, three men and two women, participated in the workshop.

1.15.9 Participant Compensation

Youth participants received a \$25 gift card to a store of their choice to thank them for their participation in the research project. While scheduling interviews with the youth, I asked for which store they would like to receive a gift card. The gift cards were given to the youth prior to their interview and we made a note of their receipt on their consent form or attached paper. The Elders received an honorarium that was based on the recommendation of one of the Indigenous governments for Elder participation in workshops. The honoraria for the Elders' were mailed to them in the form of a cheque from Memorial University of Newfoundland. Although none of the participants withdrew from the study, if a participant had withdrawn, they would have still received the honorarium.

1.16 The workshop

Our participatory filmmaking and HIV/AIDS prevention workshop took place February 13–16, 2015 at the middle school in Happy Valley-Goose Bay. The components of the workshop are described below (Appendix D).

1.16.1 HIV/AIDS education session

There were three HIV/AIDS education sessions given by the HIV educator from Healing Our Nations. Middle school aged youth attended their session on the first evening. The high school aged youth attended a session the following day. Likewise, the Elders participated in a session with the HIV educator on the second day.

1.16.2 Filmmaking

The majority of time at the workshop was spent making films. After the youth had participated in the session with the educator from HON and been oriented to the filmmaking equipment and basics, the youth participants brainstormed a list of topics of interest as a group. The group then narrowed down the topics and smaller groups were formed as youth chose the topics they were most interested in. The facilitators guided the participants, in four groups, through the process of script-writing, filming, acting, and editing. During the last afternoon, as a large group, we watched each film. Each small group made an editing plan for their film at the end of the session so that the facilitators could do any final touch ups their film required.

Workshop participants created four films during the workshop. These films include: “Our Body is a Treehouse,” a one-minute Claymation film made by three youth participants which discusses personal boundaries and the use of alcohol and other drugs; “Tested,” a three-minute film performed by four youth participants which portrays a character’s experience with STBBI testing, stigma/bullying, and social support; “Young Genius,” a three-minute film performed by four youth participants which portrays a youth’s connection to family/social support; and “Condom in Grandma’s Bag,” a six-

minute film created by the Elders and one youth participant (who also participated in another film) in which they discuss what Elders used to understand about sexual health, what they were taught growing up, and what they know now about HIV/AIDS and sexual health.¹¹ The final copies of the films were mailed to the participants on DVD. The films are owned by the youth and Elders who created them. After completing their films, they gave me permission to use their films in presentations and in my research.

1.16.3 Other workshop activities

The workshop itself was an iterative process. We had a general plan, but it was flexible, which allowed the workshop to be adapted to the group who attended. For instance, we added daily sharing circles to the schedule as requested by an Elder.

1.17 Community Debut

On April 23, 2015, we hosted a community debut of the films at the theatre in Happy Valley-Goose Bay. All of the workshop participants except one Elder attended this gathering. There were more than seventy people in attendance, bringing together people of many age groups, parents, friends, siblings, Elders, and other community leaders. It also brought together people from the different Indigenous communities in Labrador. The participants, both the Elders and the youth, presented their films to the audience and accepted questions from audience members. For some youth this was the first time they had ever been on stage and the first time they had addressed an audience. I

¹¹ These films are available to view through the following links.
Our Body is a Treehouse: <http://youtu.be/YbarAGZjJ44>
Young Genius: <https://www.youtube.com/watch?v=bTrFmh2BYig>
Tested: https://www.youtube.com/watch?v=HVhwEVIEX_E
Condom in Grandma's Bag: <https://www.youtube.com/watch?v=FyeaVDvivDk>

presented the youth participants with a gift of plasticine (due to the interest in Claymation) and a notebook after the film debut.

Our community film debut was followed by a reception and then musical performances that were part of the HIV/AIDS Labrador Project's Red Ribbon Show.

1.18 Ongoing community dissemination

In November 2015, we were invited to present the films at the Labrador Creative Arts Festival in Happy Valley-Goose Bay. The participants introduced their films and showed them to the audience of over 200 people. The films have also been shown at conferences and I have reported findings from this research project at a number of local, national, and international conferences and gatherings during the writing of this thesis.

1.19 Data Collection

As indicated, a mixed methods approach to research uses both qualitative and quantitative methods to investigate a research question. This study used both qualitative and quantitative methods.

1.19.1 Pretest and Posttest

A pretest and posttest design was used to measure knowledge and attitude change resulting from participation in the workshop. Youth participants completed a short demographic survey and a modified version of the 18-item HIV-KQ (Carey & Schroder, 2002) and "Your Beliefs" attitude scale, a validated 10-item Attitude Questionnaire from Assessment Instruments for Measuring Student Outcomes: Grades 7 – 12 (Popham et al., 1992) (see Appendix E). The pretest was completed by the youth during the first evening of the workshop after we had opened the workshop and done introductions (prior to any

HIV/AIDS information sessions). The posttest was complete during the final afternoon of the workshop.

1.19.2 Interviews

Approximately two weeks after the workshop, the youth and Elders were invited to participate in an interview. All eleven of the youth and four of the five Elders participated in interviews. I conducted, digitally recorded, and transcribed verbatim all of the interviews.

The participants were asked where they would like their interview to take place. Most interviews took place at participants' homes or in a room at the local college building. The interviews ranged in length from thirty to ninety minutes. Several participants chose to be interviewed together. In some cases, parents or guardians remained in the room while the interview was conducted. In other cases, parents were nearby or absent during the youth's interviews.

I began each interview by reminding the participants and their guardians, if applicable, that this workshop and interview was part of my doctoral research project, they were free to withdraw at any time and, if they withdrew, they would keep their honoraria. After obtaining ongoing informed consent and assent, I showed the films to the youth and parents or guardians and then discussed the plans for the community film debut and for releasing the films on the internet. Then, the parents or guardians usually retreated into the background while the participants and I talked about their experiences at the workshop based on the interview guide (see appendix F).

I offered the youth the opportunity to colour or draw during their interview as a way to increase their comfort while discussing their experiences with me. Most of the youth took me up on this offer and I provided them with markers and paper.

1.20 Films

Due to the nature of the Elders' film which discusses their perceptions of their knowledge change, I included its transcript with the Elders interview transcripts for content analysis. The other films were not analysed as part of this dissertation as the research questions guiding this dissertation were concerned with evaluating HIV/AIDS knowledge and attitude change after the workshop and an in-depth exploration of the participants' experiences using an arts-based strategy for HIV/AIDS prevention.

1.21 Data Analysis

1.21.1 Qualitative Data

Content analysis is a strategy for making meaning from text data (Hsieh & Shannon, 2005). I used content analysis to identify emerging themes in the qualitative data including transcripts from the Elders' film and interviews in order to stay as close to the words and thoughts of the participants as possible (Hsieh & Shannon, 2005). In my analysis of the experiences of youth and Elders at the workshop, I did not have predefined codes; the codes emerged from the data. I grouped emergent codes into overarching themes and subthemes. When analysing the data regarding knowledge and attitude change, I used a few predefined codes such as "knowledge change" or "attitude change."

The interviews were digitally recorded and I transcribed each recording word for word. I read each transcript through from beginning to end. Then I reread each transcript and line by line, or thought by thought, I noted what the participant was talking about as keywords. After completing this, I looked at the keywords across all interviews and grouped them into themes and subthemes. I also made note of thoughts I had about the data as I read through the transcripts, making connections to my observations, the literature, and what the other participants said. In the findings of each paper, I discussed the similarities and differences of the participants' experiences through the themes and subthemes that emerged, related them to the literature, and discussed what new contributions these findings bring to the literature.

1.20.1.1 Rigour in Qualitative Research

There are many different strategies for assessing rigour or quality in qualitative research (for examples see Krefting, 1991; Lather, 1993; Lincoln & Guba, 1985; Lincoln & Guba, 1986; Lincoln, Lynham, & Guba, 2011; Morrow, 2005; Morrow & Smith, 2000; Morse, 2015; Patton, 2002; Richardson, 1994; Tracy, 2010). Lincoln and Guba (2005) propose four criteria for establishing trustworthiness and thus, rigour, in qualitative research which are used widely for research conducted within social constructivist as well as participatory paradigms. The four criteria include credibility, dependability, transferability, and confirmability. All of these criteria were addressed in this study through the adaptation of the appropriate strategies outlined by Lincoln and Guba (2005). Each of these strategies will be outlined below. Some strategies, such as reflexivity, address more than one criterion.

Credibility refers to the establishment of “confidence that the results (from the perspective of the participants) are true, credible, and believable” (Forero et al., 2018, p.3). Strategies for enhancing credibility used in this research project include prolonged engagement, persistent observation, reflexivity, triangulation, member checking, and peer examination. Prolonged engagement and persistent observation were built into my community-based research approach. I spent extended periods of time in the community to increase my understanding of community dynamics, expectations, and interactions. Being present, observing, and making notes throughout the workshop helped me to understand and contextualize the participants’ experiences when interviewing them. It also allowed me to build relationships with the participants. This could have had an impact on their openness in the interviews (Krefting, 1991). In order to address reflexivity, I kept an audit trail and journaled about the meetings I had in the community, decisions we made about the workshop, and reflections on my experiences, the research process, and literature to increase the credibility of the findings. This journaling contributes to the credibility of the research by increasing my reflexivity, allowing me to locate myself within the research process (Lincoln, Lynham, & Guba, 2011). Additionally, throughout the interviews I member checked with the participants by reiterating what they were saying to me to see if I understood correctly. I also reframed and repeated interview questions to make sure the participants and I shared an understanding of the questions. I also member checked research findings during my subsequent trips to Happy Valley-Goose Bay (i.e., presentations to research participants and partners, as well as to other community members). The research findings were

subject to peer examination as I discussed them with colleagues who were experts in the field and presented them in conference settings to other academics and knowledge users with expertise in this area.

Transferability refers to the applicability of the findings to other contexts. As is the case with many qualitative studies, the intention of this study was to be exploratory and descriptive, not to be generalizable. However, by providing thick description of the research processes, context, and participants, as I have done, readers will be able to decide how relevant and applicable these findings may be in other contexts. The context specific nature of these findings is also identified in the sections outlining the limitations of the study.

Dependability refers to the consistency of the findings and that “the process through which findings are derived should be explicit and repeatable as much as possible” (Morrow, p. 252). Strategies for addressing dependability include “providing a rich description of the study methods” and “establishing an audit trail” (Forero et al., 2018, p. 3). In order to address dependability, I kept an audit trail of methodological decision making throughout the research and I provide a rich description of the research process allowing the reader to assess the repeatability of the study.

Confirmability refers to “the confidence that the results would be confirmed or corroborated by other researchers” (Forero et al., 2018, p.3). Strategies for enhancing the confirmability of the findings include keeping an audit trail, being reflexive, and triangulation. As stated, I kept an audit trail of decision making related to the research as well as a journal of my own thoughts and reflections. Additionally, I triangulated

multiple data sources to increase the confirmability of the research findings. Overall, I addressed the rigour of the research findings by using many strategies to attend to the four criteria for establishing rigour as identified by Lincoln and Guba (1985).

In addition to attending to the aforementioned strategies for addressing rigour in qualitative research, I also attended to strategies related to quality for participatory research. Cargo and Mercer (2008) outline several criteria to consider in participatory research approach which include “mutual respect and trust; capacity building, empowerment and ownership; and accountability and sustainability” (p. 336-337). In my research, mutual respect and trust was developed through my prolonged engagement in the community and by using a community-based research approach through which decision making on the research process and program development was shared with my research partners and other stakeholders including youth. Additionally, I was invited by the research partners to work on this research project and I received letters of support from them. Likewise, I addressed capacity building through the community-based research approach whereby community was involved in the research process. In partnership with the Canadian Aboriginal AIDS Network (CAAN), I also coordinated a community-based research capacity building workshop which was open to the whole community. Additionally, capacity was built in HIV prevention through the development and implementation of the workshop with the research partners. Empowerment and ownership in the research were addressed by following the principles of OCAP®, the community-based approach, as well as the capacity building and many knowledge sharing activities. Accountability was addressed by following the tenets of community-

based research whereby research decision-making was shared with the research partners and other stakeholders. I addressed sustainability through the prolonged engagement with the research partners and community, through extensive knowledge sharing activities in the community, and by supporting the development of their (successful) application for program funding for arts-based HIV prevention programming from PHAC.

1.21.2 Quantitative Data

We used a modified knowledge change assessment tool (18-item HIV-KQ (Carey & Schroder, 2002)) and attitudes questionnaire (“Your Beliefs” (Popham et al., 1992)) that have been validated in the literature and previously used with similar populations. Responses from the pretest and posttest were entered and analysed in R Project—statistical analysis software (2013). To examine whether knowledge levels had changed over the course of the workshop, correct responses from the knowledge questionnaire were coded “1,” incorrect responses and “don’t know” were coded as “0.” Correct answers were tallied for a maximum possible score of 18 for each participant. Responses to the attitudes questionnaire were assigned a score of “1” if they were in agreement with the evidence of risk of transmission and “0” if their response was not in line with the risk of transmission. The number of correct answers was counted for a maximum possible score of 10 for each participant. The pretest and posttest scores from the knowledge questionnaire and attitudes questionnaire were tallied and analyzed separately. A matched pair t-test was used to compare mean pretest and posttest scores. Significance was set at $p < 0.05$.

Due to the small sample size, the data were examined to determine whether statistical inferences could be made. The Shapiro-Wilk normality test indicates that both the HIV knowledge and attitude scores came from normal distributions (HIV knowledge $W(10) = 0.929$, $p = 0.441$; HIV attitudes $W(10) = 0.896$, $p = 0.197$). The results of the Wilcoxon signed-rank test offer further support of significant positive improvement in post-intervention scores, without relying on the normality of the differences (HIV knowledge $p = 0.006$; HIV attitudes (0.013)). Further information on the pretest/posttest instruments and analysis are provided in the first manuscript.

There are limitations of this quantitative analysis. The participants were self-selected; they were not representative. Thus, findings from the quantitative analysis are not generalizable. However, the intent of this study was not to generate generalizable findings. Rather, the intent was to provide an in-depth analysis of the participants' knowledge and attitude changes and experiences using participatory filmmaking in the context of HIV/AIDS prevention and education. Again, while the findings are not generalizable, it is my intention to provide sufficient context and detail that readers may assess whether this type of workshop could have a similar impact in their contexts.

1.22 Budget

Funding for this research project was received from multiple sources. I received a project grant from the Atlantic Aboriginal Health Research Program and the Laverne Monette award from the Canadian Institutes of Health Research's Social Research Centre in HIV Prevention. I also received several grants from the Northern Scientific Training Program, which helped to defray the costs of doing research in the North. My doctoral

studies were funded by a grant from the Atlantic Aboriginal Health Research Program (2012–13), a doctoral research award in community-based HIV/AIDS research from the Canadian Institutes of Health Research (CIHR, 2013–16), and the Dean’s Award from Memorial University of Newfoundland (2016-2017). Additionally, I received a fellowship in Interdisciplinary HIV Research from Universities Without Walls, which helped fund a community-based research capacity building meeting that I hosted at the LFC in Happy Valley-Goose Bay.

1.23 Summary

This introduction provided a brief overview of my doctoral research study. It described the state of the literature on arts-based HIV/AIDS prevention programming for Indigenous youth and exposed a gap in the literature regarding the evaluation of such initiatives. It also described how this research project came to be and the research questions, as well as the methodology and methods for inquiry and analysis. It also provided detail on the development and implementation of the arts-based workshop. The three manuscripts that follow present findings from this study. As stated, the first manuscript describes changes in the youth participants’ HIV/AIDS knowledge and attitudes over the course of the participatory filmmaking workshop. The second manuscript describes the youth’s experiences participating in a participatory filmmaking and HIV/AIDS prevention workshop. The third manuscript describes the experiences of community Elders participating in an arts-based HIV/AIDS prevention program for Indigenous youth. These manuscripts are followed by a conclusion that sums up the research findings, limitations, and implications of this research.

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2. Evaluating knowledge and attitude change among participants in a participatory filmmaking and HIV/AIDS education workshop for Indigenous youth

2.1 Abstract

Although arts-based HIV and AIDS education and prevention initiatives with Indigenous youth have become increasingly popular, there is a paucity of research on their use, development, appropriateness, effectiveness, and acceptability. The aim of this study was to evaluate Indigenous youths' HIV and AIDS knowledge and attitude change after participation in an arts-based HIV and AIDS education workshop.

Eleven self-identifying Indigenous youth, ages eleven to seventeen, attended a 3.5-day participatory filmmaking workshop hosted as part of a community-based research project examining the use of arts in HIV and AIDS prevention with Indigenous youth in Labrador. Participatory filmmaking was used to engage youth and create dialogue about HIV and AIDS, sexual health, and health in general.

A mixed methods design was used to assess knowledge and attitude change post-workshop. Youth completed pre and post-test surveys immediately before and after the workshop. Approximately two weeks later, youth were interviewed about their experiences. Using content analysis, interview transcripts were analyzed for themes related to HIV and AIDS knowledge and attitude change.

Post-workshop knowledge and attitude change was statistically significant. On average, participants improved their HIV knowledge scores by nearly 22% and their attitude scores by 18% after the workshop. Analysis of the interview transcripts revealed that the participants: 1) learned what HIV is; 2) learned how HIV is transmitted; 3)

learned about stigma; 4) operationalized new knowledge; 5) learned about self-efficacy: boundaries/healthy relationships; and 6) attributed their knowledge and attitude change to the environment created through participatory filmmaking.

These findings suggest that participatory filmmaking is a promising strategy for HIV and AIDS education and prevention with Indigenous youth. Improving HIV and AIDS knowledge and attitudes is essential to addressing the overrepresentation of Indigenous youth affected and infected by HIV and AIDS in Canada (NAYCHA, 2010).

2.2 Background

This manuscript is published in the *Journal of Indigenous HIV Research* (Landy, 2018) and presents findings from my doctoral research, a community-based research project exploring and evaluating the use of the arts in HIV and AIDS education and prevention with Indigenous¹² youth. I was approached by the coordinator of the Labrador HIV and AIDS Project and asked to assist in developing, implementing, and evaluating an arts-based, HIV and AIDS education program for the Indigenous youth they serve. Together, we aimed to develop an arts-based workshop that was strengths-based, culturally-safe, educational, and engaging.

In Canada, there is a need for culturally-relevant, engaging, and effective HIV and AIDS education for Indigenous youth, as Indigenous people face a disproportionate burden of disease including overrepresentation in rates of HIV infection (Adelson, 2005; Gracey & King, 2009; PHAC, 2014). The Public Health Agency of Canada (PHAC)

¹² Indigenous Peoples traditionally living in Labrador include the Inuit (Nunatsiavut), Southern Inuit (NunatuKavut), and Innu (Innu Nation recognized as a First Nation in 2002). The term Indigenous is used throughout this paper to be inclusive of the participants in this study who self-identified as First Nation, Inuit and Innu and/or Indigenous.

(2014) estimates that HIV infections rates are more than three times higher within Canada's Indigenous population than the non-Indigenous population. In addition to being disproportionately affected by HIV, PHAC estimates that Indigenous Peoples tend to contract HIV at a younger age (ten years younger) than the general population (PHAC, 2014) and often receive treatment at later stages of the disease (Nowgesic, 2015). In Canada, Indigenous youth have a higher risk of contracting HIV than do their non-Indigenous counterparts (PHAC, 2014). Indigenous youth, in particular, "are more likely to be diagnosed late, more likely to have an earlier onset of acute illness, less likely to received optimal medical care, and have shorter survival rates" (Smillie-Adjarkwa et al., 2013).

The factors that determine health are biologically, socially, politically, and environmentally driven (Adelson, 2005; Loppie Reading & Wien, 2009; PHAC, 2014; Richmond & Ross, 2009). Health disparities between Indigenous and non-Indigenous populations are related to factors such as the ongoing legacy of colonialism (Adelson, 2005; Gracey & King, 2009). For example, poverty, racism, unstable housing, mental health and addictions, the residential school system, intergenerational trauma and the loss of autonomy, self-governance, and traditional ways of life and lands contribute to poorer health outcomes among Canada's Indigenous Peoples, including higher rates of HIV infection (PHAC, 2014).

Traditional public health approaches are not adequate for addressing HIV and AIDS within Indigenous populations, as they do not account for the unique factors (such as the impact of colonialism) that increase the risk of transmission and determine health

for Indigenous people (Flicker et al., 2014). Innovative health promotion strategies that address the determinants of Indigenous health and factors that increase the risk of HIV infections must be developed in order to curb infection rates. In particular, prevention strategies for Indigenous youth should adopt decolonizing approaches and address the social factors that contribute to the elevated risk of HIV infection for Indigenous youth (Flicker et al., 2013).

Arts-based initiatives have emerged as promising strategies for health promotion in recent years with a variety of populations (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012). Genres of art, such as painting, music, and theatre have been used to in health education initiatives such as learning about stroke, hand hygiene, heart disease, chronic pain, tobacco use, and sexual health, with target audiences including children, youth, adults, men, and women around the world (Boydell et al., 2012; Williams & Noble, 2008). Arts-based education initiatives have also been increasingly used as strategies for HIV and AIDS prevention with and by Indigenous youth in Canada (Fanian et al., 2015; Flicker et al., 2013; Lys et al., 2016; Lys, Gesink, Strike, & Larkin, 2018; Lys, Logie, & Okumu, 2018; Ricci, Flicker, Jalon, Jackson, & Smillie-Adjarkwa, 2009).

Arts-based HIV and AIDS education programming is compatible with many of the wise practices for HIV and AIDS education for Indigenous youth. Ricci and colleagues (2009) published a scoping review that identified “Wise Practices” for HIV and AIDS education and prevention with Indigenous youth, which included arts-based approaches (p. 29). Peer-education and other strategies that address the impact of colonialism have been identified as effective tools for education with Indigenous youth

and can be incorporated into arts-based education (Larkin et al., 2007; Lys et al., 2016; Lys, Logie, & Okumu, 2018; Majumdar, Chambers, Roberts, 2004; Mikhailovich & Arabena, 2005; Ricci et al., 2009; Wilson et al., 2016). Lys and colleagues (2016) created an HIV prevention and leadership development program for Indigenous girls in the Northwest Territories that used the arts as a method of engagement. They found that participants in their program increased their knowledge of STBBIs including HIV after participation (Lys, Logie, & Okumu, 2018). As well, arts-based programming can strengthen community relations by involving many members of the community (Riecken et al., 2006). Additionally, arts-based programs can be empowering (Boydell et al., 2012; Finley, 2008; Flicker et al., 2014; Lys et al., 2016). For instance, Flicker and colleagues (2014) reported that Indigenous youth participating in an arts-based HIV and AIDS prevention initiative found it to be empowering as “arts-based approaches typically offer participants an opportunity to: participate equally in the decision-making process; learn and share new skills; create counter-narratives that make visible previously hidden or silenced aspects of their identity or experience; and build on or reclaim their cultural identities or cultural practices” (2014, p.19).

Although there are many initiatives that use arts-based approaches for HIV and AIDS education and prevention, there is little research available discussing their use, development, appropriateness, effectiveness, and acceptability. Evaluating arts-based programming has challenged some of the traditional strategies for evaluation, in part due to their complexity as well as the multitude of impacts and audiences (Boydell et al., 2012; Parsons & Boydell, 2012). In this research project we collaboratively developed

and assessed an arts-based strategy (i.e. participatory filmmaking) for HIV and AIDS prevention and education with Indigenous youth. This manuscript presents a description of the arts-based strategy developed, an assessment of the youth's knowledge and attitude change after the workshop, and an exploration of the participants' perceptions of what they learned about HIV and AIDS at the workshop.

2.3 Methods

In order to evaluate knowledge and attitude change during participation in the arts-based workshop, mixed methods data collection strategies were employed (Creswell, 2013; Tashakkori & Teddlie, 1998). Data sources included the instruments to assess knowledge and attitudes about HIV and AIDS pre- and post- workshop, and in-depth interviews with participants after the workshops had concluded. Using a mixed methods approach allowed for a more comprehensive understanding of the youth's knowledge uptake and attitude change after participation in the workshop.

As stated, this mixed methods evaluation of the participants' knowledge and attitude change is part of a larger community-based research study examining the use of the arts as a participatory and culturally-relevant strategy for HIV and AIDS education with Indigenous youth. This community-based research project was undertaken as a partnership between the author and the HIV and AIDS Labrador Project based in Happy Valley-Goose Bay, Labrador. The research process and workshop development were guided by the HIV and AIDS Labrador Project coordinator and advisory committee,

discussions with the community youth and other stakeholders, the principles of OCAP®¹³ (ownership, control, access and possession over research), and a review of relevant literature.

Ethics approval was granted from the Newfoundland and Labrador provincial Health Research Ethics Board (NL HREB #14 147) and NunatuKavut's research review board. Information about this study was shared with Nunatsiavut throughout the research process.¹⁴

2.3.1 The Workshop

The workshop was held in Happy Valley-Goose Bay to make it accessible to as many youth as possible. Happy Valley-Goose Bay is the largest community in central Labrador with a population of approximately 6408 people, 2965 (46.3%) of which identified as Aboriginal on the 2016 Census (Statistics Canada, 2017). In 2016, approximately 6.3% of the population identified as First Nations, 31.2% of the population identified as Inuit, and 13.8% of the population identified as Métis¹⁵ (Statistics Canada, 2017). Additionally, the HIV and AIDS Labrador Project's office is in Happy Valley – Goose Bay, although they provide programming throughout many of the communities in Labrador.

¹³ OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). www.FNIGC.ca/OCAP.

¹⁴ Nunatsiavut's research review board only reviews research conducted on Nunatsiavut lands. The Innu Nation had no official research ethics process at the time of this research.

¹⁵ Members of NunatuKavut were at one time referred to as Métis, but this term is outdated. Members of NunatuKavut refer to themselves as Southern Inuit.

The genre of arts was determined by informal consultations with youth in the community that were held by youth group coordinators and arranged by research partners. Youth were asked to rank their interest in different types of arts including painting, hip hop, filmmaking, carving and drumming, and were invited to add their own suggestions. The youth were predominantly interested in learning about filmmaking. Therefore, we developed a 3.5-day participatory filmmaking and HIV and AIDS education workshop which took place over a long weekend.

Youth ages 11-26 who self-identified as Indigenous were invited to participate in the study. Participants were recruited by word-of-mouth. A recruitment poster was circulated on community listservs, at community buildings around town, and on Facebook. Eleven self-identifying Indigenous youth (3 males and 8 females) between ages of eleven and seventeen participated in the workshop (eight middle school aged youth and three high school aged youth). Each participant gave written informed assent and a guardian signed the informed consent form prior to the youths' participation in the research study. Participants received a \$25 gift card honorarium for their participation in the workshop.

The workshop was divided into two sections: an HIV and AIDS education session with an educator from Healing Our Nations (HON),¹⁶ and filmmaking. Middle school and high school-aged participants attended separate sessions tailored to their age group with the HON educator. The education sessions included information about boundaries, healthy relationships, alcohol and other drugs, sexually transmitted and blood borne

¹⁶ Healing Our Nations is an Indigenous HIV and AIDS education organization based in eastern Canada.

infections (STBBIs), and an HIV and AIDS basics presentation: what HIV and AIDS are, how HIV develops into AIDS, and HIV transmission, prevention, and treatment. The sessions also included educational games and crafts and open discussions. Stigma was not explicitly raised by educators but emerged as a discussion topic among the participants during the workshop.

The remainder of the workshop was spent learning filmmaking skills, engaging in group-building activities such as icebreaker games, sharing meals and snacks, and participating in sharing circles led by the Elders. Professional facilitators were hired to provide instruction on filmmaking during the workshop. Two of the three film facilitators were young (under 30 years old) Indigenous people from outside Labrador. They provided technical instruction, the equipment, and facilitated each of the filmmaking groups. The youth learned how to plan a film, as well as how to film (set up shots), perform, direct and edit. The majority of time each day was dedicated to learning how to make a film (see appendix A for workshop schedule).

Participants made four short films in groups of three to six people. The participants began by brainstorming a list of topics as a group. The group narrowed down the film topics and smaller groups were formed as youth chose the topics they were most interested in. The youth made three films: “Tested,” “Young Genius,” and “Our Body is a Treehouse.” A fourth film, called “Condom in Grandma’s Bag”, was initiated by the Elders.

The first two films were written, filmed, performed and edited by youth. “Tested” was made by 4 female participants and portrayed themes of stigma, STBBI testing, and

supporting friends. “Young Genius” was created by 2 female and 2 male participants. This film portrayed themes of bullying and support from family, “Our Body is a Treehouse” is a Claymation film written, performed and created by 2 male and 1 female participants. This film built on the phrase “our body is a treehouse” which was used by the HIV educator in her discussion of personal boundaries and healthy relationships. One youth worked on two films. He was part of the group that made the Claymation film, and he also participated in the Elders’ film, “Condom in Grandma’s Bag”, taking the role of interviewer, asking the Elders what they knew about HIV in the past and what they know now. At the end of the workshop, any final edits that remained to be finished were indicated by the youth on an editing plan to be completed by the film facilitators after the workshop. Additionally, the facilitators added credits to the films that described the research project and acknowledged the funders.

2.3.2 Instruments

Two instruments were combined to form the pre- and post- test in order to assess changes in HIV knowledge and attitudes. The validated 18-item HIV Knowledge Questionnaire (Carey & Schroder, 2002), which is internally consistent, stable, sensitive to the change resulting from intervention was used to assess HIV knowledge change. Additionally, this questionnaire is appropriate for use with low-literacy populations (Carey & Schroder, 2002). We also used the “Your Beliefs” attitude scale, a validated 10-item Attitude Questionnaire from *Assessment Instruments for Measuring Student Outcomes: Grades 7 – 12*, to assess attitude change (Popham et al., 1992). Participants were required to indicate “true”, “false”, or “don’t know” to each of the statements on

both instruments. These instruments were chosen because they had been successfully used previously by the HIV and AIDS Labrador Project to evaluate school-based information sessions (not arts-based programming).

A semi-structured interview schedule was developed to explore the youth's experiences at the workshop and to provide a more comprehensive understanding of knowledge and attitude changes that occurred during the workshop. The interview schedule included questions about why youth chose to participate in the workshop, the youth's experiences at the workshop, knowledge of HIV and AIDS, and filmmaking as a strategy for HIV and AIDS education.

2.3.3 Data Collection

Participants answered all questions on the self-administered pretest when they first gathered for the workshop and on the posttest they completed at the end of the weekend workshop. Participants' pretests and posttests were matched by unique identifying numbers. Unique identifying numbers, all data, and materials from the workshop were stored securely in my locked office.

Approximately two weeks after the workshop, participants were invited to be interviewed about their experiences at the workshop. All of the 11 participants were interviewed either alone or in pairs depending on whether the participant(s) chose to be interviewed together. Two sets of siblings participated in the interview process together. The interviews were conversational and lasted thirty to ninety minutes. The interviews were digitally recorded and transcribed verbatim. I started the interviews by showing the participants (and their parent/guardian, if present) their film and asking if it had been

completed according to the group's editing plan and if there were any other changes they would like to make. In most cases, the parent/guardian, if present, left the room after watching the film. In two cases, parents/guardians were present for the full interview. In those cases, the parents/guardians both withdrew to a corner of the room during my conversation with the participant.

2.3.4 Data Analysis

Responses from the pretest and posttest were entered and analysed in R Project—statistical analysis software (2013). To examine whether knowledge levels had changed over the course of the workshop, correct responses from the knowledge questionnaire were coded “1,” incorrect responses and “don't know” were coded as “0.” Correct answers were tallied for a maximum possible score of 18 for each participant. Responses to the attitudes questionnaire were assigned a score of “1” if they were in agreement with the evidence of risk of transmission and “0” if their response was not in line with the risk of transmission. The number of correct answers was counted for a maximum possible score of 10 for each participant. The pretest and posttest scores from the knowledge questionnaire and attitudes questionnaire were tallied and analyzed separately. A matched pair t-test was used to compare mean pretest and posttest scores. Significance was set at $p < 0.05$.

I used a conventional content analysis approach to code interview data that focused on knowledge change and attitude change (Hesse-Biber & Leavy, 2010; Hsieh & Shannon, 2005; Miles, Huberman, & Saldana, 2013). Interviews were audio recorded and transcribed verbatim (in full). Each transcript was read multiple times to get an overall

sense of the data (youth's experiences). Microsoft Word was used for data management and to assist with coding. Individual words and phrases regarding knowledge uptake and attitude changes regarding HIV and AIDS were coded. These codes were developed into the themes presented.

2.4 Findings

2.4.1 HIV knowledge and attitudes Pre- and Post- Arts-Based Workshop

Due to the small sample size, the data were examined to determine whether statistical inferences could be made. The Shapiro-Wilk normality test indicates that both the HIV knowledge and attitude scores came from normal distributions (HIV knowledge $W(10) = 0.929$, $p = 0.441$; HIV attitudes $W(10) = 0.896$, $p = 0.197$). The results of the Wilcoxon signed-rank test offer further support of significant positive improvement in post-intervention scores, without relying on the normality of the differences (HIV knowledge $p = 0.006$; HIV attitudes $p = 0.013$).

On average, participants answered 5.7 (SD 2.45) out of 18 questions correctly on the HIV knowledge pretest and 9.6 (SD 2.88) on the posttest. Participants answered an average of 5.7 (SD 3.13) out of 10 questions correctly on the HIV attitudes pretest and 7.5 (SD 2.59) on the posttest.¹⁷

¹⁷ One participant had an 18-point increase between the pretest and posttest, having answered, "Don't Know" to every statement on the pretest. This unusual 18-point increase was an outlier in the data. This participant did not have exceptionally different (from average) pretest or posttest scores; the 18-point improvement post workshop is almost 3 standard deviations above the average improvement (z -score = 2.78). Including the outlier the knowledge pretest and posttest means were 5.2 (SD 2.89) and 9.4 (SD 2.84) respectively on the knowledge questionnaire and 5.2 (SD 3.43) and 7.6 (SD 2.50) respectively on the attitudes questionnaire. The outlier is excluded from further analysis.

Matched paired t-tests indicate that the changes in scores between the pretest and posttest are statistically significant ($t_{(9)} = 8.093, p < .001$). Participants' HIV knowledge scores increase on average by approximately 4 additional correct answers post-workshop ($MD = 3.9, SD = 1.52; 95\% CI (2.8, 5.0)$).

Participants' HIV attitudes scores increased on average by approximately 2 additional correct answers post-workshop ($MD = 1.8, SD = 1.55; 95\% CI (0.7, 2.9)$). This is a significant positive improvement ($t_{(9)} = 3.674, p = .005$) (see Table 1, below).

Table 1. Pretest and posttest comparison of participants' HIV knowledge and attitude scores (n=10)

	MEAN PRETEST	MEAN POST TEST	MEAN DIFFERENCE (95% CI)	TEST- STAT (t_{10})	P- VALUE (p)
HIV KNOWLEDGE	$\bar{x} = 5.7$	$\bar{x} = 9.6$	MD = 3.9, (2.8, 5.0) SD = ± 1.52	$t_{10} = 8.09$	$p < 0.001$
HIV ATTITUDES	$\bar{x} = 5.7$	$\bar{x} = 7.5$	MD = 1.8, (0.7, 2.9) SD = ± 1.55	$t_{10} = 3.67$	$p = 0.005$

2.4.2 Emerging themes on HIV knowledge and attitudes

Qualitative content analysis of the interview data increases the understanding of the quantitative findings by providing breadth, depth, and context to the quantitative data. It also allows for a comparison of the data and findings from each data collection method to occur (Creswell, 2013). The findings from the qualitative analysis support the quantitative findings as they suggest that participants learned about HIV and AIDS over the course of the workshop. To further this, many youth attributed their learning to participation in the workshop.

Through qualitative content analysis, the following themes regarding HIV and AIDS knowledge and/or attitude change emerged from the interviews. These themes

include 1) the participants learned what HIV is, 2) the participants learned how HIV is transmitted, 3) the participants learned about stigma, 4) the participants operationalized new knowledge, 5) the participants learned about self-efficacy: boundaries/healthy relationships, and 6) the participants attributed their knowledge and attitude change to the environment created through participatory filmmaking.

1) The participants learned what HIV/AIDS is

Participants had a range of HIV and AIDS knowledge prior to the workshop. Several youth reported that they did not know what HIV and AIDS was prior to attending this workshop. Other participants were familiar with other STBBIs but did not know about HIV and AIDS prior to the workshop.

I: Okay, that was the first time you had heard about HIV? Okay, had you heard about other STIs before?

P: Well, I know chlamydia or whatever.

2) The participants learned how HIV is transmitted

When asked about what they learned at this workshop, many youth indicated that they learned about how HIV was transmitted. For instance, one group of youth decided to focus their film on educating people about how HIV is transmitted:

We learned that there is only three ways¹⁸ that you can get HIV. So we used that in our film. Like at first we didn't know, most of us didn't know what it was. So we just, once we learned about it we decided to make our film based on that because a lot of people don't know what it is.

In addition to learning how HIV is transmitted, many of the youth learned how it is *not* transmitted.

¹⁸ The “three ways” this participant is referring to is through blood, breastmilk and semen/vaginal/anal secretions.

I: What did you learn about [HIV/AIDS]?

P: Well, I didn't know that, it can like, when you touch people, you can't get it.

3) The participants learned about stigma

Although not specifically addressed in the HIV/AIDS information session, stigma regarding HIV, AIDS, STBBIs and testing emerged in the discussions during the workshop as well as in the films and in the interviews. One youth connected reducing stigma and not being afraid of contracting HIV to having more knowledge about how it is transmitted:

Even if you got HIV or any of that stuff, you don't got to be scared you can catch it or anything because you can only get it through certain things and why you shouldn't make fun of them because this happens to some people and sometimes they don't even know they have got it.

Some youth indicated that they were using the opportunity to make films to educate others about HIV and non-stigmatizing attitudes:

The film that it is helping people understand more, like how we talked about how you can't just catch it just from touching someone, ... we are helping people learn that it is okay to be around people, you can't just block them out.

Another youth stated, "We learned about different ways that you can get HIV, how to not get HIV and to get tested." Some youth related stigma to the reasons people do not get tested for HIV/AIDS.

I: Do you think that is a big problem that people that people don't want to get tested because ...?

P: They think people are going to make fun of them.

I: Yeah? Do you think that that happens?

P: Yeah.

I: Yeah? And so what do you want to tell people by making this film, what was your message?

P: That if a person have HIV or STIs, they shouldn't go away because you can't you can't like, I don't know how to explain it.

I: You are doing a good job. Because you can't...like you can't catch it?

P: Yeah.

I: From?

P: It is not like a flu or nothing.

4) Operationalizing knowledge

Several of the youth made films that operationalized their new knowledge during the workshop. Several youth felt they had a duty to educate others about what they did not previously know. They used the opportunity to make a film to educate their audiences about HIV/AIDS. For instance, one group made a film called "Tested."

P: Well, we made a film about, we were bullying a girl because she got tested for HIV and then we started spreading rumours about it and [...] and stuff.

I: Why did you think it was important to make that film?

P: So that people would know not to make fun of people and stuff.

I: And was it made because of things that you learned at the workshop?

P: Yeah.

I: Like what?

P: Like we learned that there is only three ways that you can get HIV so we used that in our film. Like at first we didn't know, most of us didn't know what it was, so we just, once we learned about it we decided to make our film based on that because a lot of people don't know what it is.

I: Did you know anything about HIV before?

P: No.

I: This is the first time you had heard about it?

P: Yeah.

Additionally, another youth described operationalizing her new knowledge in her own life during a playground interaction during the period between the workshop and the research interview.

P: On Friday [a boy in the playground] was like, don't touch me I have HIV. I was like, I explained to him, you can't get, I cannot get HIV from touching you.

I: So the bully¹⁹ was saying that you shouldn't touch him? Or the boy was saying it?

P: The boy was on Friday when I went to school, this boy was like don't touch me I have HIV and I was like, I cannot get HIV by touching you.

I: and what did he say to that?

P: he said, oh, he said, oh, I didn't know that, yeah.

5) Self-efficacy²⁰: Boundaries, Healthy relationships

Another theme that emerged from the data was the idea of having boundaries, including ownership and control of one's body. The youth used the metaphor, "Our body is a treehouse" from their HIV/AIDS education session in one of the films. Several of the youth described learning about having control over what happens to their body when talking about what they learned at the workshop. "We learned that our body is kind of like a treehouse, like you have rules." Another youth stated, "Kids and teenagers can make their own choices about what they do to their body." Another youth related this metaphor to having respect for herself. In particular, she felt it was important to have boundaries when negotiating [sexual] relationships in the future. She stated,

P: I learned that your body is a treehouse, that you got to respect your body and for me, I would rather be with someone I know and all that before we get serious.

I: so you would have a good relationship with somebody before.

P: and I will set some boundaries.

6) Knowledge and attitude change as a result of participation in participatory filmmaking

All of the youth reported learning about HIV/AIDS at the workshop. Some youth described learning from the HIV/AIDS educator and other facilitators, some youth

¹⁹ The participant had previously referred to the other youth as a "bully."

²⁰ Bandura (1990) describes self-efficacy as people's ability to "exert control over their motivation and behavior and over their social environment" (p. 9).

described learning from their peers through the process of participatory filmmaking and others described learning from other groups' films.

I: Did you know some of those things before?

P: The only think I knew about that is that you could only get it like from if you have sex and all that.

I: And so have you ever thought about the bullying for people who were getting tested or might have HIV.

P: No.

I: No? You never thought about that before? That was just something you guys thought about when you were talking all together?

P: Yeah.

2.5 Discussion

The findings of this study suggest that during the participatory filmmaking and HIV and AIDS education workshop youth increased their level of knowledge and improved their attitudes related to HIV and AIDS. Post-workshop change was significant for HIV knowledge scores ($t_{(9)} = 8.093, p < .001$) and HIV attitudes scores ($t_{(9)} = 3.674, p = .005$). Interview data supported the quantitative findings and expanded upon these findings by providing details regarding what the participants felt they learned at the workshop.

Analysis of the interviews indicated that participants had a range of HIV knowledge prior to the workshop. Beyond learning of the existence of HIV, both the questionnaires and interviews confirmed that youth learned how HIV is transmitted. Although knowledge increased significantly after the workshop, knowledge levels remained low with an average correct response rate of 53.3 percent on the HIV knowledge posttest, an approximately 21.7 percent increase in correct responses. The participants' attitudes towards HIV and AIDS improved on average by 18.0 percent after

participation in the workshop to an average correct response rate of 75.0 percent. The change in attitudes appeared to be related to learning about HIV transmission, including about which body fluids contained HIV. One potential reason knowledge remained low is that the HIV education session was not tailored to specifically address the questions on the test.

Giles (2014) conducted a similar assessment of a (non-arts) school-based HIV and AIDS education intervention in Labrador. Her study included 91 youth ages 11 to 17, 54 of whom identified as Indigenous (59.3%). Participants in her study improved their scores on average by 13.3 percent on a similar knowledge questionnaire and by 2.2 percent on the same attitudes questionnaire after a 1.5 hour classroom-based information session (Giles, 2014). The participants of our participatory filmmaking workshop demonstrated a greater improvement in both knowledge and attitude scores than a similar population participating in a non-arts-based education session.

Youth attending this participatory filmmaking and HIV and AIDS education workshop identified a connection between stigma and HIV testing. Improving HIV knowledge is critical to improving HIV-related attitudes and ultimately to reducing stigma. For instance, knowing how HIV is transmitted and not transmitted can affect attitudes towards people living with HIV. Additionally, HIV stigma can be a barrier to accessing prevention services including HIV testing (Lys et al., 2016), as well as HIV treatment. Considering Indigenous people have higher rates of HIV infection and often are diagnosed at later stages of the disease (Nowgesic, 2015), reducing HIV-related stigma is crucial. The findings from this study show that youth participating in this

participatory filmmaking and HIV education workshop demonstrated increased HIV knowledge and improved related attitudes after the workshop, ultimately reducing HIV stigma among the participants.

Although the participants in this study significantly increased their HIV-related knowledge and improved their attitudes, their knowledge and attitudes scores remained low. This suggests that participatory filmmaking was a successful strategy for HIV and AIDS education but demonstrates the need for ongoing engagement and education initiatives with this population.

There are few studies that examine HIV knowledge and attitude change with this population in Canada. Although wise practices suggest HIV prevention education should begin before the age of 15 (Ricci et al., 2009), many HIV education initiatives and assessments do not include youth under the age of 15. The findings of this study suggest that participatory filmmaking is an effective strategy for HIV education as the participants significantly increased their HIV/AIDS-related knowledge and improved their attitudes during the workshop.

2.5.1 Operationalizing knowledge and attitude change

While the quantitative data demonstrate that there was a significant change in both HIV knowledge and attitudes among the participants, the interview data provides a much more nuanced understanding of how knowledge and attitudes changed as a result of the workshop.

Something not captured by the HIV knowledge questionnaire was how youth were able to operationalize their new HIV-related knowledge. For instance, one youth

recounted a playground interaction which occurred during the period between the workshop and the participants' interviews that demonstrated her HIV knowledge and her confidence to challenge a "bully" with that knowledge. Another youth spoke about wanting to set boundaries in future relationships. Many of the youth spoke about how they wanted to educate their peers by informing others of their new knowledge through their films. The youth operationalized their new knowledge, in this case through filmmaking with the desire to educate their peers. Overall, these findings suggest that the youth were empowered by the knowledge gained through their participation in the workshop. These findings are in line with others who have found participatory arts-based health promotion initiatives to be empowering for participants including with Indigenous youth and Indigenous women (Boydell et al., 2012; Finley, 2008; Flicker et al., 2014; Prentice, 2015). Additionally, these findings are promising as research suggests increasing feelings of empowerment, self-esteem, and self-efficacy can have protective qualities with regards to HIV infection (King, 1999; Lys & Reading, 2012; Prentice, 2015; UNAIDS, 2014).

2.6 Limitations

This was a descriptive pretest and posttest study which evaluated HIV/AIDS knowledge and attitude change without a comparison or control group. The design of this study is limited to assessing change over time. The change measured post workshop may not be solely due to workshop participation. An additional limitation of this study is that knowledge and attitude changes were only measured immediately after the workshop.

Ongoing assessment at greater time intervals would provide information on whether participants retained what was learned during the workshop.

The findings of this study are not generalizable due to the small (n=10), non-representative sample of self-selected participants, and lack of comparison group. Additionally, the small sample size did not allow for data to be analyzed by participant's gender or age. We were also not able to report on participant's ethnicity beyond participants identifying as Indigenous; ideally, youth would be able to report whether they identify as Innu, Inuit, First Nations, or Metis, for example. However, the significance of the change in knowledge and attitudes suggests that it may be fruitful to conduct a similar study with a representative sample of participants.

The HIV-KQ questionnaire provides limited assessment of knowledge regarding the “natural history, clinical course, or treatment of HIV and AIDS” (Carey & Schroder, 2002, p. 6) Therefore, an additional limitation of the questionnaire is that it only addresses sexual vectors of transmission and does not include other vectors of transmission such as intravenous drug use (IDU) which is the most common mode of HIV transmission among Indigenous people in Canada (Carey & Schroder, 2002; PHAC, 2014). Additionally, this HIV knowledge assessment tool, although adapted and piloted with this population (Giles, 2014), was not actually developed for use with Indigenous youth.

2.7 Conclusion

This study is the first to evaluate knowledge and attitude change among Indigenous youth engaging in participatory filmmaking as a strategy for HIV/AIDS

prevention. Youth significantly improved their HIV/AIDS knowledge and attitudes during their participation in the workshop. These findings suggest that participatory filmmaking is a promising strategy for HIV/AIDS education and prevention with Indigenous youth. Improving knowledge and attitudes and the resulting reduction in stigma are essential to curbing the overrepresentation of Indigenous youth affected and infected by HIV/AIDS in Canada.

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3. Experiences of Indigenous youth participating in an arts-based HIV/AIDS education workshop

3.1 Abstract

Globally, arts-based approaches are becoming increasingly popular strategies for health promotion initiatives with Indigenous youth, in part due to their ability to engage participants. However, there is a paucity of research discussing how these strategies are developed and received by participants. The aim of this study was to develop, implement, and evaluate an arts-based strategy for HIV/AIDS education with Indigenous youth. This article explores the experiences of Indigenous youth attending a participatory filmmaking and HIV/AIDS education workshop in Labrador, Canada.

Eleven youth and five Elders from the diverse groups of Indigenous people in Labrador attended a 3.5-day filmmaking workshop. Participants created dialogue about HIV/AIDS, sexual health, and health in general through participatory filmmaking. Following the workshop, the youth were interviewed about their experiences using participatory filmmaking as a strategy for HIV prevention and education. Interview transcripts were analysed using thematic content analysis. Four major themes emerged from the data: i) the youth found participatory filmmaking an acceptable and engaging strategy for HIV/AIDS education; ii) participatory filmmaking allowed youth to create an environment in which they learned; iii) the process of participatory filmmaking facilitated the development of relationships among youth and between youth and Elders; iv) the youth viewed themselves as HIV/AIDS educators.

The findings of this research study suggest participatory filmmaking is a promising arts-based approach for HIV/AIDS education and prevention with Indigenous youth, providing a good platform for constructive dialogue and engagement among youth, as well as between youth and Elders. Additionally, the workshop contributed to the development of knowledge, skills, and a desire to be educators among the youth who participated. These findings are critical for developing effective HIV/AIDS education with Indigenous youth in order to reduce HIV/AIDS infection rates in this priority population. Further research is required to examine the use of participatory filmmaking as a strategy for developing peer leadership in the context of HIV/AIDS education and prevention.

3.2 Background

There is a need for culturally-relevant, engaging and effective HIV/AIDS education for Indigenous youth, as Indigenous people continue to be overrepresented in rates of HIV infection in Canada (PHAC, 2014). HIV infections rates are more than three times higher within Canada's Indigenous population than non-Indigenous people living in Canada (PHAC, 2014). In addition to being overrepresented in this pandemic, Indigenous people tend to contract HIV at a younger age (ten years younger) than the general population (PHAC, 2014) and do not receive treatment until later stages of the disease (Nowgesic, 2015). Additionally, in Canada Indigenous youth have a higher risk of contracting HIV than their non-Indigenous counterparts (PHAC, 2014). Indigenous youth, in particular, "are more likely to be diagnosed late, more likely to have an earlier

onset of acute illness, less likely to received optimal medical care, and have shorter survival rates” (Smillie-Adjarkwa et al., 2013).

Indigenous health is determined by biological, social, political, and environmental factors (Adelson, 2005; Greenwood, De Leeuw, Lindsay, & Reading, 2015; Loppie Reading & Wien, 2009; Richmond & Ross, 2009; Smylie, 2013). Health disparities between Indigenous and non-Indigenous populations are fuelled by Indigenous determinants of health which include factors such as the ongoing legacy of colonialism which include poverty, racism, intergenerational trauma and the loss of autonomy, self-governance, and traditional ways of life and lands (Adelson, 2005; Gracey & King, 2009; Greenwood, De Leeuw, Lindsay, & Reading, 2015; Loppie Reading & Wien, 2009; Richmond & Ross, 2009; Smylie, 2013). For this reason, public health approaches such as campaigns aimed at individual behaviour change, basic knowledge-based campaigns, or ABC (abstinence, be faithful, condomize) campaigns are not adequate for addressing HIV/AIDS within Indigenous populations, as they do not account for the unique factors that increase the risk of transmission and determine health for Indigenous people (Flicker et al., 2014). Health promotion strategies that address the determinants of Indigenous health must be developed in order to curb infection rates.

Arts-based initiatives have emerged as innovative and promising strategies for HIV/AIDS prevention with Indigenous youth in Canada. Ricci and colleagues (2008) published a scoping review that identified “Wise Practices”²¹ for HIV/AIDS education

²¹ The term “Wise Practice” has been adopted by some in this field including the Canadian Aboriginal AIDS Network as they feel this term is more culturally relevant than “best, good, or promising practices. The premise is that wisdom is knowledge put to use” (Barlow et al., 2008, p.12).

and prevention with Indigenous youth that included arts-based approaches (p. 29).

Several research projects have begun to explore aspects of arts-based HIV prevention for Indigenous youth. For instance, Lys and colleagues (2016) created an HIV prevention and leadership development program for Indigenous girls in the Northwest Territories using the arts. Likewise, Flicker and colleagues developed Taking Action and Taking Action II, an arts-based HIV prevention program for Indigenous youth that was implemented in 6 communities across Canada (Flicker et al., 2012; Flicker et al., 2013; Flicker et al., 2014; Wilson et al., 2016). Participants in this study used the arts to explore links between HIV and colonialism.

In addition to research on HIV prevention initiatives, many people are using the arts to engage Indigenous youth. For instance, Chee Mamuk (2009) published “A Guide to Wise Practices for HIV/AIDS Education and Prevention programs” include tips on using the arts in their programming. Additionally, the Canadian website, *Youth, the Arts, HIV and AIDS* (YAHAnet.org) showcases various types of art-based projects created by youth, including Indigenous youth, promoting HIV awareness and education.

Arts-based strategies fit within many theories of learning. These theories include social learning theory whereby people learn from each other through imitation, observation, and modelling (Bandura, 1977), as well as social justice-oriented empowerment theories such as the development of critical consciousness, which refers to the ability to understand how oppressive forces (e.g. the impacts of colonialism) govern one’s life and to take action against them (Freire, 2000).

Arts-based approaches can also be used as a decolonizing strategy within research whereby they aim to address colonialism and challenge behaviours, attitudes and beliefs that propagate colonialism (Castleden, Garvin, & “Huu-ay-aht First Nation”, 2008; Flicker, 2013; Prentice, 2015). Correspondingly, regarding the use of decolonizing strategies in terms of approaches to HIV prevention, Flicker and colleagues (2014) report that

arts-based approaches typically offer participants an opportunity to: participate equally in the decision-making process; learn and share new skills; create counter-narratives that make visible previously hidden or silenced aspects of their identity or experience; and build on or reclaim their cultural identities or cultural practices. (p.19)

Although initiatives using the arts for HIV/AIDS education and prevention with Indigenous youth have become increasingly popular, there is little research available discussing their use, including their development, effectiveness, and acceptability. The aim of this study was to develop, implement, and evaluate arts-based strategies for HIV/AIDS education with Indigenous youth. This manuscript examines the experiences of Indigenous youth participating in a 3.5-day participatory, arts-based, HIV/AIDS education workshop to better understand how youth participate and learn in an arts-based setting. Additionally, this manuscript aims to make Indigenous youth’s voices heard as they continue to be described as a priority population in HIV prevention.

3.3 Methods

A community-based research (CBR) approach was adopted in order to develop, implement, and evaluate arts-based strategies for HIV/AIDS prevention with Indigenous youth in collaboration with the HIV/AIDS Labrador Project. CBR is an approach that aims to equitably involve non-academic partners at all stages of the research process (Israel, Schulz, Parker, & Becker, 1998; Minkler, 2005). Given the impact of HIV/AIDS on Indigenous youth, and the research supporting peer education initiatives, involving youth meaningfully in HIV/AIDS prevention and education is crucial to the development of relevant programs and resources. Hence, this CBR approach also aimed to include youth as partners in the research who had control over the development of the workshop and their experience at the workshop.

This study was undertaken as a partnership between me (a non-Indigenous doctoral student) and the HIV/AIDS Labrador Project based in Happy Valley-Goose Bay, Labrador. Staff at the HIV/AIDS Labrador Project identified a need for engaging and effective programming and an interest in how arts-based programming could serve this purpose. We aimed to develop an arts-based workshop that was strengths-based, culturally-relevant, educational, and engaging. The research process and workshop development were guided by the HIV/AIDS Labrador Project coordinator and Advisory Committee, discussions with community youth and other stakeholders, and a review of relevant literature.

Ethics approval was granted from the Newfoundland and Labrador provincial Health Review Ethics Board (NL HREB #14 147) and NunatuKavut's Research

Advisory Committee. Information about this study was given to Nunatsiavut throughout the research process.²²

The genre of art for the workshop was determined by informal consultations with community youth that were arranged by the research partners. Youth were asked to rank their interest in different types of arts including painting, hip hop, filmmaking, carving, and drumming and were invited to add their own suggestions. Youth were predominantly interested in learning about filmmaking. Therefore, we developed a 3.5-day participatory filmmaking and HIV/AIDS education workshop.

The workshop included a session with an educator from Healing Our Nations, an Indigenous HIV/AIDS education organization based in Eastern Canada. During the workshop, participants attended an HIV/AIDS education session with the educator, learned about filmmaking, made films, and engaged in group building activities (i.e., icebreaker games and sharing circles led by Elders; see appendix D). The middle school youth and high school youth attended different sessions with the HIV/AIDS educator. The sessions with the HIV/AIDS educator included information about boundaries, healthy relationships, alcohol and other drugs, sexually transmitted and blood-borne infections (STBBIs), and an HIV/AIDS basics presentation. The sessions also included educational games and crafts and open discussions. Information included what HIV/AIDS is, how HIV develops into AIDS, how it is transmitted, how HIV can be

²² Nunatsiavut's research review board only reviews research conducted on Nunatsiavut lands. The Innu Nation had no official research ethics process at the time of this research.

prevented, and how HIV is treated. The topic of stigma around HIV or testing was not explicitly raised by educators but emerged as a discussion topic.

Eleven self-identifying Indigenous youth between the ages of eleven and seventeen participated in the workshop. Each youth participant gave written informed assent and a guardian signed the informed consent form prior to the youth's participation in the research study. Five Elders from the Indigenous groups in Labrador also participated in the workshop. The Elder participants gave informed consent prior to participating in the research.

The participants made four short films in groups of three to six people. Film facilitators provided technical instruction and coached each group through the process of filmmaking. The participants brainstormed a list of topics as a group. The group narrowed down the film topics and smaller groups were formed as youth chose the topics they were most interested in. The youth made three films: "Tested," "Young Genius," and "Our Body is a Treehouse". One youth also participated in the Elders' film, "Condom in Grandma's Bag." The films are not analyzed in this manuscript as the aim of this manuscript is to explore the youth's perceptions and experiences using participatory filmmaking as a strategy for HIV/AIDS prevention. Hence, approximately two weeks after the workshop, I invited the youth participants to be interviewed about their experiences at the workshop. All youth participants agreed, and were interviewed either alone, or in pairs, and in some cases with parents or guardians present. The interviews were semi-structured, conversational, and lasted 30 to 90 minutes. I digitally recorded the

interviews and transcribed them in full. I used qualitative content analysis to identify themes emerging in the interview transcripts (Hsieh & Shannon, 2005).

3.4 Findings

Through qualitative thematic analysis, four major themes emerged from the data. These themes included that the youth were engaged by the workshop, the youth learned at the workshop, relationships were developed at the workshop, and the youth viewed themselves as educators at the workshop. Each of these themes contained multiple subthemes. These themes and subthemes are heavily intertwined and will be discussed individually for clarity.

3.4.1 The youth were engaged

Interview data suggested that the youth were engaged in the workshop. The youth participants were interested in filmmaking and described their experiences at the workshop as fun and social, which contributed to their overall engagement. The youth were genuinely interested in this arts-based approach. Many chose to participate in this workshop over other events going on in the community, including the Valentine's Day dance (normally attended by most youth) that was held in the same venue as the workshop. Additionally, youth identified the desire to learn filmmaking as their primary reason for attending the workshop. One youth described her interest in attending the workshop, stating, "Mostly, I just wanted to learn how to film." She furthered this by stating, "Yeah, I was going to go to the dance first but then I was like and then when you guys came in, I was kind of like, I want to go there instead." When asked why she came

to the workshop, another youth stated that she wanted “to learn how to use cameras.” Another stated he participated because he “wanted to make a film.”

Many of the youth participants were interested in the workshop because they thought it would be a social opportunity. One youth explained that she, “wanted to be with my friends for the weekend and participate and make a film and stuff.” Another participant stated that her motivation for attending the workshop was linked to both the social opportunity and the opportunity to learn about filmmaking. She said she attended the workshop “to meet new people and we get to have a good experience and we get to learn stuff.”

Overall, most youth were very interested in learning how to make their own films and this was a major consideration in their desire to participate in the workshop. Although the youth identified the opportunity to learn how to make films as the primary reason that they attended the workshop, most youth also said they would have come to the workshop even if we did not offer filmmaking. Only one youth stated he would not have been likely to attend if we had not offered filmmaking.

The youth had fun at the workshop. They found the process of filmmaking to be enjoyable and described several factors as contributing to their enjoyment. These factors include creating bloopers, acting, and needing to redo scenes due to laughter. Additionally, many youth described the social nature of the workshop as contributing to their fun.

Many youth found having to redoing scenes due to bloopers to be part of what made their experience fun. For instance, when asked what made the workshop fun, one youth stated,

P: Having to do some scenes over and over again.

I: Yeah? And so why did you guys do the scenes over and over again?

P: Because, because, because it wasn't. Because it was like when we started laughing in the middle of a scene.

I: Was it funny to be in characters?

P: Yeah.

Similarly, another youth found the experience of acting to be fun. She stated,

I: So what was it like to make your film?

P: It was pretty fun.

I: What made it fun?

P: All the acting stuff.

Some youth felt that they connected with their peers by coaching each other through the filmmaking process. For instance, when I asked what it was like to work with her group of four youth, one participant explained,

Well, it was really good. It was really funny too because whenever we made a mistake, we would look at [one of the facilitators] or something and then I had asked [participant] what my lines were for half of them and she was like [participant] say thing, okay, you got to say this, stay in character, don't do that, don't laugh.

The participants enjoyed the social environment created through the process of participatory filmmaking. The youth made films in groups and many youth found working in groups to be fun. For instance, one participant found the process of filmmaking fun because it was social. When asked if she enjoyed the workshop, she stated, “Yeah, I met lots of new people and shooting the films was fun.” Another youth reported that seeing her peers having fun contributed to her enjoyment. When asked what made the experience fun she explained, “Seeing other people have fun too.” Similarly, another youth felt the social nature of filmmaking contributed to her fun:

I: What was the most fun part of it?

P: I think just watching them as they filmed, like the first couple and the rest of the scenes, like the ones I didn’t film and just watching it go along, the boys just um, messing around at some points, like in between breaks.

Several participants stated that they do not think they would have enjoyed the workshop as much if the youth had made films individually. They felt that the social nature of the workshop and process of participatory filmmaking was critical to their enjoyment of the experience:

I: Do you think it would have been different if you made a film by yourself?

P: Yeah. That would be bad though.

I: Why would it be bad?

P: Because it would be like...frustrating, like, I don’t know.

Overall, several factors contributed to the youth’s enjoyment of the workshop. To reiterate, these factors included their interest in filmmaking, acting, bloopers, and the

social nature of the workshop environment. All of the participants indicated that they had a good time at the workshop. Additionally, when asked if they would change anything about the workshop, most youth stated that they would not change anything.

3.4.2 The youth learned

The youth participants found the workshop to be educational. In particular, youth indicated that through their participation in the workshop they learned about filmmaking, HIV/AIDS, and stigma related to HIV and STBBI testing. Youth attributed their learning to the environment created through participatory filmmaking. These subthemes will be discussed below. Additionally, the youth indicated that they learned about Indigenous culture through their participation; this will be discussed under the theme “relationships were built.”

Many youth indicated that they learned about filmmaking and developed filmmaking skills through their participation in the workshop. Most of the participants indicated that they had never made their own films or used filmmaking equipment (e.g., video cameras, microphones, editing software) prior to the workshop. However, as stated previously, many of the participants expressed great interest in learning these skills.

The filmmaking skills learned by the youth varied. One participant spoke about how he learned to set up a film shot. Another participant talked about learning that “there is different points of view for the directing.” Another participant stated that she learned “that you can shoot a short film in three days” and another explained, “I learned about the cameras. They can be confusing.” When asked what he will always remember about the workshop, one youth stated he will always remember “how to set up a camera.”

Additionally, many youth gained an appreciation of the work that goes into filmmaking. One youth stated that she learned “just how much work goes into making films” and that “it takes a lot of shots for just one little scene.” Another youth shared, “I think it was actually kind of cool how such very little, well, such long time could make such a little time video.”

Many youth also learned about HIV/AIDS and sexual health by participating in this workshop. For some youth, this workshop was the first time they heard about HIV, others spoke about learning how HIV was transmitted, and several youth mentioned that this workshop was this first time they thought about stigma related to HIV. Many youth connected learning to filmmaking, either making their own film or watching their peers’ films. Each of these sub-subthemes is discussed below.

The youth had varying levels of prior knowledge about the HIV/AIDS. Several youth stated that they did not know what HIV was prior to attending the workshop. One youth stated, “The HIV surprised me, because I didn’t know what that was.” Some youth knew about other STIs but had not heard of HIV before:

I: Okay, that was the first time you had heard about HIV? Okay, had you heard about other STIs before?

P: Well, I know chlamydia or whatever.

Some youth indicated they had learned about HIV in their grade seven curriculum, and one youth who had participated in the grade seven curriculum felt this workshop was beneficial because it reinforced what they had previously learned. However, several said they did not remember anything from grade seven.

Several youth identified that they learned about how HIV is transmitted at the workshop. One youth stated that through the filmmaking she learned that HIV was only transmissible “by blood, breastmilk and sexual fluids.” Another youth explained: “Well, I didn’t know that, it can like, when you touch people, you can’t get it.”

Many youth felt that participatory filmmaking directly contributed to what they learned about HIV/AIDS. For instance, some youth connected their learning about HIV/AIDS directly to making films in this participatory context. One youth felt that making a film allowed her to talk about topics that she felt shy talking about. She reported thinking that “it is better to make a video instead of talking because you get shy talking about that.”

Another youth stated that her group made the film about HIV testing because of what they learned at the workshop: “Well, where you were learning about it and all that, and then we thought it would be a good idea and then we found out it was hard work, like getting used to saying it and all that.” For this youth, having information about HIV/AIDS, such as the ways the virus is transmitted, meant that she learned about it by repeating the lines over and over (or hearing the lines repeated over and over). The repetition of the information inherent in filmmaking contributed to her learning.

Some youth felt they learned because the workshop was participatory and engaging, and some youth felt this environment was more conducive to learning than a traditional educational environment. One youth stated that he felt he learned more through this participatory filmmaking workshop than he would have in a classroom setting due to its engaging, participatory nature:

I: What did you learn by making a film at an HIV workshop about HIV or health?

P1: Hmm.

P2: That you can only get it three ways and it is not contagious unless you interfere with the three ways.

I: And do you think that because you made a film about getting tested that you learned it better than if you were in a classroom?

P2: Yeah.

I: Why?

P: Because teachers only teach up at the board or something and like, yeah.

Several other youth also described the participatory filmmaking workshop to be a better learning environment than a classroom or school-based setting. Another youth described the engaging and embodied nature of participatory filmmaking and related it to her learning:

I: Do you think that you learned more about HIV and about health by making a film than you would if you were just in school?

P: Yeah, because I get it when I actually act it out or because in school I got to write it over and over to get it.

I: But when you did it by film, you had to perform it so you thought the performing was useful for learning?

P: Yeah.

I: What about the performing? What about it made it good?

P: Well, when, because me, I am a really shy person, because in school I only hang out with my friends. I don't talk to no one different at all. So I found that we get to do, when we were there we got to talk to anyone and I got kind of out of my shyness. I am not as bad as I used to be.

I: Yeah? What made you get out of your shyness?

P: All the people there and talking to everyone.

Some participants related other aspects of the filmmaking process to their learning. For instance, some youth described the repetition required, as well as the embodied nature of performance, as effective strategies for learning. Many youth also felt these characteristics made participatory filmmaking a better learning strategy than traditional didactic classroom-based learning. One youth explained this, when prompted:

P: I think that it is better to make a film about it because you have to repeat over and over to get the line right, and also that if a teacher is teaching it in front of the class like, you don't know if you are paying attention to her or him and when you are actually filming it you have to, I don't know.

I: You actually have to participate?

P: Yeah.

I: You have to be there listening and acting?

P: Yeah

I: And being engaged? Do you know what 'engaged' means? [*Participant indicated yes.*]...yeah? So do you think making a film it makes you do all those things?

P: Yeah.

I: How?

P: Because you are acting it out I guess. And you have to participate in it and get your lines right.

Another youth described filmmaking as a good way to learn about HIV/AIDS because she felt it was easier to talk about issues that may be considered sensitive in character:

I: Do you think that film was a good way to work and to talk about those kinds of things?

P: Yeah.

I: Why?

P: It is easier to do it when you are in different character because if you go straight up to someone and tell them they would get it but it is easier expressing it when you are making a film I find.

Another youth found that filmmaking was a good platform for HIV/AIDS education because of its social nature and the creation of a social and open environment. He said filmmaking was a good strategy for HIV/AIDS education because of the interactions between participants. He felt that this process made a 'fun' learning environment:

I: Do you think that making a film was a good way of coming together and learning?

P: Yeah.

I: What made it a good way?

P: Interaction with one another.

I: And why do you think it is good to interact with one another when you are learning? Or in general, why do you think it is good to interact?

P: Because it makes things a lot easier and it makes things more fun.

I: Ah, cool. Do you think that making films is a way to learn things?

P: Yeah, it can be a way to learn things.

Some participants felt that filmmaking was a good strategy for HIV/AIDS education because of its visual and embodied nature:

I: How do you think it helps you learn?

P: Some people don't learn by just writing, some people learn by visual so it would be good for people who learn visually and there is a lot of people that learn visually.

Similarly, another participant felt that their learning was enhanced by the embodied nature of filmmaking: "It helps you learn because, like, you are doing it physically." Likewise, another participant felt that the opportunity to role play and embody a character through making a film could allow people to think through the possibilities of their behaviour and actions: "A character can be like a role model or something of it and the role model influences you and it could change the way you do things."

Another youth felt that the participatory nature of filmmaking created an engaging and interactive environment for the youth to participate in the workshop. He felt that this was the best way for youth to engage in learning about HIV and sexual health:

I: What other ways do you think would be good for learning about HIV or sexual health, or other kinds of health issues?

P: I think that [filmmaking] is the best way.

I: And why is it the best way?

P: Because everyone who is making the video participates and they learn when they interact. Because I know myself, I teach kids and when I get them to participate and interact, they really learn.

I: What do you think it is about participating and interacting that helps learn?

P: I guess because when they just talk to you, they get bored and they start to daydream and lose track of what you are doing and, keep it interesting.

I: And so it keeps interest by being really participatory?

P: Yeah.

Only one youth stated that he felt he did not learn about HIV by making a film. This could have been because the film he worked on did not directly address issues of HIV/AIDS, as his group made a film about how family and social support is integral to health and wellbeing. However, he felt like he did learn about HIV by watching the other groups make films:

I: Do you think you learned about HIV and health by making the film?

P: Uh, uh, not really.

I: What did you learn by watching [other participant's] film?

P: That you can get it three ways.

I: Was that something that you didn't know before?

P: I didn't know that.

I: No? But because you watched their film, that was something that you learned?

P: Mmhmm.

Similarly, another youth described learning by watching the other youth's films.

In addition to learning from other youth's films, she described integrating this new knowledge into her understanding of herself and desires for future relationships. Based on watching the other group's film, "Our body is a treehouse" she stated, "I learned your body is a treehouse, that you got to respect your body and for me, I would rather be with someone I know and all that before we get serious...and I will set some boundaries."

The youth expressed learning about stigma related to HIV/AIDS through participation in the workshop, and they readily related the concept of stigma to their understandings of bullying. For instance, one group made their film about a girl who is going to get tested for HIV and STIs who confides in her friend only to have her friend spread rumours about her. The group described this film as being about bullying and that the message of the film was to not bully or spread rumours and to educate others on the ways that HIV is actually transmitted. One of this film's creators related bullying and stigma as reasons that people do not want to be tested for STIs:

I: So how does your film relate to HIV and AIDS and things that you learned at the workshop a couple weekends ago?

P: I think it relates by this girl getting teased because she got tested for it and then everyone makes fun of her so, then afterwards, she finds out she didn't have it. So then everything became okay and everything was good.

I: Do you think that it is a big problem? That people don't want to get tested because

P: They think people are going to make fun of them.

I: Yeah, do you think that happens?

P: Yeah.

I: Yeah. And so what do you want to tell people by making this film? What was your message?

P: That if a person have HIV or STIs, they shouldn't go away, because you can't you can't like, I don't know how to explain it.

I: You are doing a good job. Because you can't...like you can't catch it?

P: Yeah.

I: From?

P: It is not like a flu or nothing.

Another youth described having some knowledge of how HIV is transmitted prior to the workshop but had never thought about stigma related to HIV or testing. She stated that through the process of making films and having discussions with her peers, her group explored the topic of stigma and bullying related to getting tested and being HIV positive:

I: Did you make that film because of the things that you learned at the workshop?

P: Yeah.

I: Yeah? What did you know before? Did you, was that all things you learned? Or did you know some of those things before?

P: The only thing I knew about is that you could only get it like from if you have sex and all that.

I: And so had you ever thought about the bullying for people who were getting tested or might have HIV?

P: No.

I: No? You never thought about that before? That was just something you guys thought about when you were talking all together?

P: Yeah.

This participant went on to discuss not stigmatizing people with HIV or STIs. She stated,

Even if you got HIV or any of that stuff, you don't got to be scared. You can't catch it or anything because you can only get it through certain things and why you shouldn't make fun of them because this happens to some people, and sometimes they don't even know they have got it.

Overall, the youth found this workshop to be educational. They described learning about filmmaking, HIV/AIDS and stigma. The environment created through this participatory filmmaking and HIV/AIDS education workshop was a space where youth felt comfortable engaging and learning.

3.4.3 Relationships developed

Participatory filmmaking facilitated social connections among youth and between youth and Elders at the workshop. Youth enjoyed working with their peers to create films and found that this social approach to filmmaking contributed to their fun and the development of friendships. The youth found the group filmmaking process facilitated the development of relationships between them. Some youth suggested that if the filmmaking was done individually, it would not have been as engaging, “It would have been a lot more boring. It wouldn’t be as interesting. I would lose focus.”

Several youth described the connections they made with group members as something that made the workshop fun:

I: So what was it like to make your film?

P: It was really fun.

I: What made it fun?

P: All the energy that [group member] and [group member] had. The imagination and the creativity they had.

The youth also enjoyed the opportunity to meet and work with people of different ages, genders, and cultural groups. One participant described learning that she could be friends with anyone at the workshop: “I learned that you could be friends with anyone. They don’t got to be a particular age or different, it could be any gender and all that and way more things I can’t explain.” Another youth enjoyed the opportunity to connect with people from different cultural groups, referring to Inuit, Southern Inuit, and Innu cultural

groups, explaining that “We got to learn about different things and stuff about different cultures.”

The youth felt that the facilitation of the group led to the creation of a comfortable environment in which they could connect with the other participants. One youth stated,

P: Well, I liked everything on what we were doing and filmmaking. I thought it was cool. It was very nice that everybody accepted each other, when somebody needed help, somebody else helped them

I: And why do you think we had such a good group?

P: Bond.

I: Yeah? And how was that made?

P: You know that little [sharing] circle at the end? I think we got to know each other when we did that.

Overall, youth felt they developed friendships and connections with their peers at the workshop.

In addition to developing relationships with their peers, the youth felt that they developed connections with Elders through their participation. As stated, five Elders representing the distinct Indigenous communities in Labrador attended the workshop. Each day, the Elders brought in items that were of importance to them to share and talk about with the youth. Some of these items included snowshoes, a sealskin whip used for dog sledding, caribou skin, books with photographs of their communities and families, and a Kudlik (traditional Inuit carved stone, seal-oil lamp). Most youth reported not knowing these Elders from their community prior to the workshop. However, over the

course of the 3.5 days together, the youth described building relationships with the Elders and all of the youth felt it was a good idea to have the Elders present throughout the weekend.

The youth viewed the Elders as educators in their community and understood the role of the Elders to include providing knowledge on HIV/AIDS and sexual health. Several youth commented that they thought it was important for Elders to be included in this workshop so that they could educate their grandchildren:

I: Did you think it was neat to hear about what the Elders were saying? About what they had learned?

P: Yeah.

I: And about how things changed? Yeah? And how it is now?

P: Yeah.

I: And do you think it is important to know? Because they kind of said that it was important for them to know.

P: So they could tell their grandchildren and all that.

I: And so what do you think about that?

P: I think it is pretty good because they could tell the information they learned from the workshop and tell it to their grandchildren and all that and when they grow up they can tell different people and all that hopefully.

Another youth spoke about how he thought it was a good idea to involve youth and Elders at the workshop because there are few opportunities for youth and Elders to interact:

I: Do you think it was good that Elders and youth were together?

P: Yes. It was very good. Because the elderly and the young interacting with each other is not, you don't see that very often these days, all you see is, like, kids on their phones and they don't do as much anymore.

Having Elders and youth participate in this workshop together allowed them to develop relationships and the youth were able to challenge some of the assumptions they previously held about older people. When asked what it was like to have Elders participate in the workshop, one youth stated,

P: I found it a surprise because I mostly think old people stay home and be grumpy.

I: Oh really, so it was a good time to have them come and have fun at the workshop too?

P: Yeah.

I: So do you think of them in a different way now?

P: Yeah.

I: Yeah? What do you think of them now?

P: Cool.

I: Yeah?

P: Yeah.

I: Anything else?

P: No. I just find them cool.

I: And so what did you find cool about them at the workshop?

P: Well, about the snowshoeing thing and the thing they put the fire, like the Inuit thing.

I: The Kudlik? Yeah.

Several youth spoke about enjoying this opportunity to learn from the Elders. In particular, some youth found it interesting to hear what the Elders knew about HIV and sexual health when they were growing up. One youth described how he liked learning about how things used to be from the Elders with regard to sexual health education, knowledge, and HIV/AIDS:

I: What did you think about having the Elders participate in the weekend?

P: I thought it was pretty good because we learned stuff from them and then we found out that we didn't have no treatment for it or anything for it when they were just growing up and all that.

Similarly, another youth liked learning about what the Elders knew about sexual health when they were growing up and how things have changed between generations. This youth felt like there was much more information available for this generation of youth and that there are many more sources of information:

P: I thought it was good because they talked about how they learned about STIs and all that when they were growing up and then what it is like now and how we could see the differences and all that.

I: Why do you think, what do you think about those differences?

P: The differences are that when they were younger they learned about it by themselves and all that and now you could learn about it from your health teacher,

your school, your guidance counsellor and you can learn about [it from] a lot of people.

Similarly, another youth expressed in learning how things were different in the past from the Elders:

I: When you were doing the filming with the Elders? How was that?

P: I liked it a lot. I learned more from the Elders and different things on how they thought HIV was in the past and now.

Another youth stated that “It was really good learning, it was really good because we, they [the Elders] talked about their past and talked about the things that used to go on and how it used to be. It was very interesting.”

Some youth were surprised about the lack of information the Elders were given about sexual health growing up:

I: What else surprised you about what [the Elders] were talking about?

P: Oh, how they didn’t know how babies were made [laughing].

I: Ah, yep.

P: They thought they came from little stump things.

The youth were not only interested in learning about the Elders’ knowledge of sexual health, they were also very interested in the cultural teachings that the Elders offered throughout the workshop. Many youth described connecting with the Elders through their teachings about Indigenous cultures, through the sharing circles, and participation in ceremony (such as lighting the Kudlik). For instance, one youth stated that “It was good” to have Elders participate throughout the workshop and reported

learning “lots of cultural things.” Similarly, another youth felt positive about youth and Elders participating together at the workshop. She also learned a lot from the Elders, including traditional knowledge:

I: What did you guys think about having the Elders participate in the workshop?

P: It is kind of great to have the Elders in the workshop.

I: What made it great?

P: Because we can learn things from them.

I: What kind of things did you learn from them?

P: This, this, I don't know his name, but with the snowshoes.

When asked what she thought about having the Elders there, another youth reported that she “liked...some of the stories they told and going outside when we lit the, is it Kudlik?...yeah and some of the stuff they brought, I liked learning about that.”

Several youth indicated that the relationships that they developed with Elders at the workshop were ongoing outside the workshop environment:

I: What do you think about making friends with people with different ages?

P1: It was nice.

I: Have you seen any of the Elders since?

P1: Yeah.

P2: Yeah.

I: Will you talk to them? You feel like you could talk to them? Like they are your friends now?

P1: Mmhmm.

P2: Yeah.

I: Did you talk to them?

P2: Yeah.

Having youth and Elders participate in the workshop broke down barriers and allowed youth to develop relationships with the Elders in their community through the use of participatory filmmaking. The youth felt it was both appropriate and necessary that Elders participated in HIV/AIDS education. Colonization disrupted traditional Indigenous ways of life, including with regard to the relationships and teachings youth may have received from Elders in their communities (Gabel, Pace, & Ryan, 2016). Analysis of the interview data revealed that filmmaking and having Elders present at the workshop perceived as a decolonizing approach whereby the participants felt empowered and engaged with traditional cultural values through their participation (Flicker et al., 2014).

3.4.4 Youth as educators

A final theme that emerged from the data is that the environment of the participatory filmmaking workshop facilitated the development of youth as educators. Through participation in this workshop, youth expressed a sense of duty or desire to be educators themselves and the nature of this participatory filmmaking workshop created an environment where youth took the role of educators.

Some participants felt that there was a need for education among their peers. For instance, one youth said she would tell their friends to come to this workshop, “because they need to know.” Another youth expressed that there is a need for information and

education about HIV transmission, and he felt that making films was both a good way to learn about HIV/AIDS and to educate other people about HIV/AIDS:

I: Do you think making films is a good way of learning?

P: Yeah.

I: What makes it a good way of learning?

P1: Because we can.

P2: Because we can learn how to film.

I: Do you think it is a good way of learning about HIV?

P: Yeah.

I: Yeah? What do you think makes it a good way to learn about HIV?

P: Because people need to know what HIV is, like, you can't get HIV just by sneezing.

I: So, you think that making films is good because you can share that message with other people?

P: Yeah.

Similarly, when asked about who should see their films, one participant felt that "lots of people" should see their film stating, "just people, so they can know about it, STIs and stuff." Another participant felt that she had learned important information about HIV prevention, sexual health, and stigma, and that there is a need for her to share this information with other people:

I: Did you enjoy making a film?

P1 & 2: Yeah.

I: What did you like about it?

P1: The message, like for everyone to see.

I: So it was important for you to make it so people could see your movie? Like you had something to tell them?

P1: Yeah.

With regard to their film, another youth stated, “I would like the younger kids to see it to know what they are going to be doing in when grow up and to adult years.”

Overall, the youth participants described their experiences at the workshop as an engaging, social, fun, and educational experience. They described learning about filmmaking, HIV/AIDS, and stigma, as well as about culture. The youth felt it was beneficial to have Elders participate in the workshop, both for the Elders’ sake as well as for their own. The youth developed relationships with their peers and with Elders. The youth also described a sense of responsibility to educate through their participation in the workshop. These findings will be discussed below.

3.5 Discussion

This study sought to explore the experiences of Indigenous youth participating in an arts-based HIV/AIDS education workshop. The youth participants experienced the workshop as engaging, fun, educational, and social. To my knowledge this is the first study to examine the use of participatory filmmaking for HIV/AIDS education with Indigenous youth. These findings are critical for developing effective HIV/AIDS education with Indigenous youth in order to reduce HIV/AIDS infection rates in this priority population.

3.5.1 Engaging youth

As stated, one of the objectives of this participatory filmmaking and HIV/AIDS education workshop was to engage youth in HIV/AIDS education and prevention. The findings of this study suggest that filmmaking was successful in drawing youth to the workshop and engaging them meaningfully throughout the workshop (including over multiple days with competing activities and foul weather in the community).

Youth were interested in participating in this HIV/AIDS workshop because they were interested in learning how to make films, they thought making films would be fun, and they thought it would be a social opportunity. One reason for their enthusiasm may have been that youth in the community were asked what types of arts they were interested in learning more about and using in this context. Additionally, youth were enthusiastic because they were working in groups and were involved in every aspect of the filmmaking process. The topics of the films were chosen by the youth from the very broad prompt of thinking about what makes us healthy and our general discussions during the workshop. As well, the youth participants described feeling engaged because they had control over the process and their experience at the workshop. Based on the description of their experiences of attending the workshop, the youth's expectations that the workshop would be educational, fun and social were fulfilled.

Arts-based health education strategies have been lauded for their ability to engage participants (Glik, Nowak, Valente, Sapsis, & Martin, 2002). This study confirms that the participants of this participatory filmmaking and HIV/AIDS education workshop were engaged in the workshop. However, arts-based strategies vary in their opportunities for

engagement, ranging from having participants observe an arts-based activity (such as a health education play or listening to music; see Landy, 2010) to facilitating youth producing their own artistic creations (Flicker et al., 2012; Flicker et al., 2013). The participants of this study felt that the participatory nature of the workshop and the control they felt over the process was critical to their engagement. Less participatory arts-based strategies may not be as engaging for participants.

A review of the literature did not find any studies discussing the use of this type of participatory filmmaking with Indigenous youth for HIV/AIDS education. However, other HIV/AIDS education and health initiatives for Indigenous youth have used arts-based approaches such as digital storytelling, painting, and hip-hop (Flicker et al., 2013; Lys et al., 2016). These approaches have been described as having the potential to be decolonizing, participatory, and engaging strategies including with Indigenous youth as participants may be empowered through the process, there may be a more balanced relationship between researchers and participants, and the voices of the participants are prioritized (Flicker, 2013; Flicker et al., 2014; Native Youth Sexual Health Network, 2015; Prentice, 2015; Riecken et al., 2006). Additionally, Riecken and colleagues (2006) suggest that filmmaking can be used “to develop culturally grounded conceptions of health and wellness resists typical [colonial] curriculum methodology” (p. 269). This is congruent with the findings of this study as the youth were empowered, they explored their own conceptualizations of health, they developed relationships with Elders, who may have traditionally had a role in youth education, and they engaged “with power

structures, cultural values, and identity development” through their participation (Flicker et al.2014, p.28).

3.5.2 HIV prevention and learning

Knowledge about HIV/AIDS prior to the workshop varied among participants; however, all participants described learning about HIV/AIDS through participation in the workshop. This suggests that this participatory filmmaking and HIV/AIDS education workshop had the flexibility to meet people where they were with regard to knowledge needs. Additionally, it suggests that the participants felt comfortable learning about HIV/AIDS in this environment.

The youth found this workshop to be educational with regard to HIV/AIDS for a variety of reasons in addition to the information given by and discussions with the HIV/AIDS educator, Elders, and each other. These reasons included the repetitive, engaging, and embodied nature of performing in film, the social environment, and the opportunity to role play. These characteristics, which are inherent in creative participatory filmmaking, were identified by the participants as effective strategies for education. These characteristics are also recognized as ways that people learn and assets of performance-based strategies of engagement (e.g. Bandura’s social cognitive theory of learning, see Bandura, 1977). This finding suggests that participatory filmmaking was able to meet people where they were at, and that there were many opportunities for learning and a variety of learning styles inherent in the process. The diversity of experiences, opportunities and ways to engage in participatory filmmaking is an asset of

this strategy as there is “something for everyone” with regard to learning styles and activities.

3.5.3 Developing peer educators

Another finding from this study was that the process of participatory filmmaking elicited a desire to educate on the part of the participants. Many youth saw their role as filmmakers with a duty to educate. This was apparent in the way youth spoke about the need for education among their peers and the intended audiences of their films. Most youth saw their films as tools for peer education or for delivering health messages to the audience although they were not asked to make educational films. This is similar to Riecken and colleague’s (2006) finding that Indigenous youth participating in their film-based health and wellness initiative positioned themselves as educators through the creation of films.

Peer education is a strategy for HIV/AIDS education that has been described as a “Wise Practice” for both Indigenous youth and other populations (Lemieux, Fisher, & Pratto, 2008; Mikhailovich & Arabena, 2005; Ricci, Flicker, Jalon, Jackson, & Smillie-Adjarkwa, 2009; Vujcich, Thomas, Crawford, & Ward, 2018). Peer education

involves training and supporting members of a given group to effect change among members of the same group. Peer education is often used to effect changes in knowledge, attitudes, beliefs, and behaviors at the individual level. However, peer education may also create change at the group or societal level by modifying norms and stimulating collective action that contributes to changes in policies and

programs. Worldwide, peer education is one of the most widely used strategies to address the HIV/AIDS pandemic. (Kerrigan & Weiss, 2000)

This finding is intriguing as peer education continues to be described as a wise practice for HIV/AIDS education and prevention (Majumdar, Chambers, & Roberts, 2004; NAYCHA, 2010; Ricci et al., 2009; Vujcich, Thomas, Crawford, & Ward, 2018). Other initiatives have used the arts as a way to engage in peer education (Glik et al., 2002; Lemieux et al., 2008; Flicker et al., 2013). However, there is little literature available on developing Indigenous peer educators (Monchalin et al., 2016). The findings of this study show that the youth participants took up the role of educator themselves. Not only were they motivated to educate through participation in this workshop, they also developed both the skills and the desire to educate their peers and others through participation in this participatory filmmaking workshop. This finding is particularly useful for program developers who would like to develop peer leadership with Indigenous youth but find little guidance in the literature. Further research is required to examine the use of participatory filmmaking as a strategy for developing peer leadership in the context of HIV/AIDS prevention and education.

3.5.4 Relationship building

The participants found the process of participatory filmmaking very social. They described developing relationships and connections with their peers as well as with the Elders present at the workshop.

Our approach to participatory filmmaking was group-based, which created a very interactive environment. Youth made their films in small groups and the remainder of the

time was spent playing games and sharing stories with the larger group. Many youth commented on how they felt this social approach of filmmaking was beneficial to both their learning and enjoyment. They suggested that a more individualistic filmmaking process would not have been as engaging, fun, or educational. Based on the youth's interviews, other kinds of participatory filmmaking, such as making films individually, may not have been as successful at engaging youth.

The term 'participatory filmmaking' has been used to describe many different uses of filmmaking, contexts and processes. Gubrium and Harper (2013) outline several different kinds of participatory filmmaking in their overview of participatory visual and digital methods including Videovoice, documentary-making, and digital storytelling, which have varying degrees of collaboration. For instance, digital storytelling is an example of a form of participatory filmmaking that is often done independently. Digital storytelling has been used in a number of different contexts including for HIV/AIDS prevention with Indigenous youth (see Danforth et al., 2014). Digital storytelling, as a genre of participatory filmmaking, has many characteristics that make it an excellent strategy for engagement and communication depending on the topics and the participants. In a recent study, Fletcher and Mullett (2016) found that a digital storytelling health promotion intervention also allowed for intergenerational dialogue and relationships to form between youth and Elders. The appropriateness of the group versus individual approaches may depend on factors such as the topic of the filmmaking, the age of the participants and their experiences, or the group.

Regarding the development of relationships between youth and Elders, Flicker and colleagues (2007) found in a study with Indigenous youth that they were interested in learning about sexual health and HIV/AIDS from Elders. They indicated that the youth in their study had a great amount of respect for Elders and at least one youth related the desired to have Elders engage in youth sexual health education to the traditional role of Elders in Indigenous communities (Flicker et al., 2007). Additionally, they found that the youth in their study felt Elders required education on these topics and should be included in health promotion initiatives. Similarly, the youth in this participatory filmmaking and HIV education workshop were interested in learning about topics including sexual health from the Elders present and found the Elders' participation beneficial and enjoyable. This suggests that the environment created through this participatory filmmaking workshop successfully contributed to a decolonizing approach that allowed for relationships to develop between youth and Elders whereby youth learned about sexual health and about culture from the Elders. Overall, the findings from our study suggest that participatory filmmaking can successfully be used as a decolonizing strategy for engaging both Elders and youth in HIV/AIDS education together.

3.5.5 Beyond HIV/AIDS education and prevention

HIV/AIDS education and prevention with Indigenous youth is best served through a culturally grounded and holistic approach to health and wellbeing. This workshop attempted to do this through a number of approaches such as including Elders in the workshop, participating in sharing circles, and providing an environment in which relationships were built. The result of this holistic approach means that this workshop

may serve not only as a strategy for HIV/AIDS education and prevention but also may, itself, contribute to the promotion of health and wellbeing. Prentice (2015) found that arts-based engagement with HIV positive Indigenous women was described as “damn good medicine” by many of her participants. She states, “While we did not design our project as an ‘intervention’, it is clear that Visioning Health worked as a holistic and integrated action for social change on several levels that are mutually reinforcing” (Prentice, 2015, p. ii). Similarly, Riecken and colleagues (2006) found that First Nations youth participating in a participatory filmmaking project developed relationships with other generations through their participation and that their participation built resiliency among First Nations youth. Likewise, in reference to mental health promotion, Kirmayer and colleagues (2013) suggest such programs,

orientated toward empowerment aim to restore positive youth mental health and a strong sense of cultural identity by giving youth an active role in designing and implementing programs that meet their needs. Health promotion, with its emphasis on empowerment, may represent a contemporary re-articulation of traditional egalitarian practices that recognised the central role of youth in the health and vitality of the community. (Kirmayer et al., 2003, p. 21)

Participation in this research study may have contributed to the development of resiliency, mental health promotion, and connection to culture among the youth through decolonizing approaches as the youth described developing intergenerational relationships. These factors were not assessed in this study; however, they should be

considered in future research endeavors as they are critical to improving the health and wellbeing of Indigenous Peoples and addressing the legacy of colonialism.

3.6 Limitations

The findings of this study are highly community specific as the development of the workshop and the aspects of the workshop were led by research participants and community members. The participants were self-selected; it is likely that only those who were interested in filmmaking and/or HIV/AIDS would sign up to participate in the workshop. Although the youth in this study were very positive about using filmmaking in this context, this does not mean that filmmaking would work well for youth in all contexts. The duration of the workshop was relatively short, and the participants were interviewed only once – two weeks after the workshop. The youth may have answered interview questions differently if their parents/guardians or siblings were not present during the interview.

3.7 Conclusion

To my knowledge, this study is the first to examine the experiences of Indigenous youth engaging in participatory filmmaking as a strategy for HIV/AIDS prevention. The findings of this research study suggest participatory filmmaking is promising as a strategy for HIV/AIDS education and prevention with youth. The youth participants found participatory filmmaking to be an engaging, fun, social, and decolonizing strategy for HIV/AIDS education. Overall, the process of participatory filmmaking contributed to the development of the youth's desire to be peer educators, increased their knowledge about

HIV/AIDS, and developed relationships with their peers and the Elders present at the workshop. All of these outcomes are essential to curbing the overrepresentation of Indigenous youth affected and infected by HIV in Canada.

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4. “Condom in Grandma’s Bag”: Experiences of Elders participating in an arts-based HIV/AIDS education workshop for Indigenous youth

4.1 Abstract

Little research examines the role Elders play and wish to play in HIV/AIDS education and prevention with Indigenous youth. This article explores the experiences of Indigenous Elders attending a participatory filmmaking and HIV/AIDS education workshop for youth in Labrador, Canada. This article also discusses how Elders perceive their role in HIV/AIDS education and prevention.

As part of a community-based research project examining the use of arts in HIV/AIDS education and prevention with Indigenous youth, eleven youth and five Elders from the various Indigenous cultural groups living in Labrador attended a 3.5-day participatory filmmaking workshop. Participants created a dialogue about HIV/AIDS, sexual health, and health in general through participatory filmmaking. Following the workshop, the Elders were interviewed about their experiences making films and working together with the youth. Interview transcripts and the Elders’ film were analysed using thematic analysis.

The three major themes that emerged from analysis included: i) the process of participatory filmmaking allowed for their “comfortable” engagement; ii) Elders co-created the learning environment; and iii) the Elders felt they developed relationships with youth.

The findings of this research suggest participatory filmmaking is a promising arts-based approach for HIV/AIDS education and prevention with Indigenous youth,

providing a good platform for constructive dialogue and engagement among Elders, as well as between youth and Elders. Additionally, the workshop contributed to the development of knowledge, skills, and the desire to be educators among the Elders who participated.

4.2 Elders and Health Promotion

Although there is no universal Indigenous culture or paradigm (Loppie, 2007), within many Indigenous communities Elders hold a place of “esteem and respect” (Flicker et al., 2015; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007). Elders are not simply people of advanced age and not all older people are considered to be Elders (Flicker et al., 2015; Iseke & Moore, 2011). Traditionally, Elders, often referred to as “knowledge keepers” (Iseke & Moore, 2011, p. 34), were responsible for providing teachings to youth and other community members on the “norms, knowledge and moral values of the whole society” (Gabel, Pace, & Ryan, 2016, p. 76). These teachings may include information and guidance regarding health promotion on topics of sexual health, childrearing, and relationships (Castellano, 2000; Hampton, McWatters, Jeffery, Farrell Racette, & Byrd, 2004; Healey, 2014).

Colonization disrupted traditional ways of life and continues to have multigenerational effects on the health and wellbeing of Indigenous people (Loppie Reading & Wien, 2009). These health disparities are apparent in the disproportionate burden of disease and ill-health faced by Canada’s Indigenous people (King, Smith, & Gracey, 2009; Loppie Reading & Wien, 2009). For instance, residential schools, one aspect of colonialism, resulted in many Indigenous people living away from their families

and communities. These generations did not have access to traditional knowledge and knowledge keepers, resulting in cultural discontinuity between generations. As a result of the ongoing impact, there are generations of Indigenous people who have not had the opportunity to participate in traditional ways of life or receive traditional teachings and hence cannot participate in the education of younger generations (Healey, 2014; Rand, 2016). Beyond this disconnect from traditional knowledge and social structures, topics around sexual health became taboo in many communities as a result of colonial beliefs and values (Healey, 2014). Some relate the taboo nature to the influence of the church, residential schools, and the lack of traditional education on the topic (Danforth, 2014; Healey 2014).

Lack of traditional knowledge and connection to culture as well as other effects of colonialism are reflected in the health disparities faced by Indigenous peoples, including the disproportionately high numbers of Indigenous people who are infected and affected by HIV. Indigenous people in Canada have a rate of HIV infection that is 3.6 times higher than the general population (PHAC, 2014). In 2011, Indigenous people comprised only 3.8% of the total Canadian population (Statistics Canada 2011), yet in 2006 Indigenous people accounted for 27.3% of positive HIV tests (Worthington et al., 2010). In addition to being overrepresented in this pandemic, epidemiological data show that Indigenous people in Canada tend to contract HIV at a younger age (on average, ten years younger) than the general population and receive treatment at later stages of the disease (Larkin et al., 2007; Nowgesic, 2015).

In order to address this disproportionate burden of poor health outcomes faced by Indigenous people in Canada, current health promotion efforts must include the impacts of colonization as a determinant of health (King, Smith & Gracey, 2009; Loppie Reading & Wien, 2009). Additionally, health promotion initiatives may be strengthened by using decolonizing and culturally appropriate approaches. For instance, including Elders in intergenerational health promotion initiatives may have many benefits and be culturally appropriate. However, very little research has explored the involvement of Elders in youth health promotion efforts and the few that I have been able to locate address smoking cessation or suicide rather than topics of sexual health (Kirmayer, Simpson, & Cargo, 2003; Jacono & Jacono, 2008; Varcoe et al., 2010).

Typically, when Elders are included in youth health promotion, it is for initiatives that address mental health through cultural continuity, which has a protective quality for aspects of Indigenous health (Chandler et al., 2003; Jacono & Jacono 2008). For instance, Kirmayer, Simpson, and Cargo (2003) involved Elders in youth suicide prevention and mental health promotion as mentors for the youth to connect them to their culture. Jacono and Jacono (2008) involved Elders in their puppetry intervention addressing Mi'Kmaq youth suicide to connect youth with traditional knowledge and culture. However, the value of Elders is seen in other areas. For instance, Varcoe and colleagues (2010) argue that the inclusion of Elders in youth tobacco reduction strategies is valuable due to their respected position in society.

With regard to sexual health education and HIV prevention, a study on the sexual health of youth by Flicker and colleagues (2008) found that Indigenous youth are

interested in learning from Elders about sexual health. They also found that youth felt Elders themselves should be educated on matters related to HIV/AIDS in order to be able to provide knowledge and guidance for youth (Flicker et al., 2008). Likewise, Smillie-Adjarkwa and colleagues (2013) found that Indigenous youth want Elders to participate in sexual health and HIV/AIDS education for youth. The authors conclude that Indigenous Elders should be included in HIV prevention with Indigenous youth (Smillie-Adjarkwa et al., 2013). Likewise, Indigenous youth participating in an arts-based HIV prevention initiative indicated that Elders should be involved in HIV prevention as supports and role models for youth (Flicker et al., 2017). Additionally, Healey (2014), in her study of sexual health communication between Inuit parents and their children, found that parents felt that Elders should be involved in the sexual health education of their children.

However, there are barriers to including Elders and adults more generally in sexual health and HIV research with youth. For instance, it is not common to involve multiple generations in sexual health promotion initiatives. Additionally, older generations may not feel comfortable talking about sexual health with younger generations. For instance, Rink and colleagues (2014) found that Inuit parents in Greenland did not feel comfortable talking about sexual health with their children. They suggest “future STI prevention efforts in Greenland would benefit from involving Greenlandic youth and their families in the design of community-based sexual health education programs that increase communication skills in families about topics related to sex” (Rink, Montgomery-Anderson, & Anastario, 2014, p.83). However, Healey (2016)

found that Inuit youth in Canada's north preferred obtaining sexual health information from their parents or caregivers over resources such as the Internet, school system, or health representative. Similar research investigating Elders' comfort levels talking about sexual health with youth and strategies for youth and Elder engagement in sexual health education and HIV/AIDS prevention are underdeveloped in the literature.

The aforementioned studies suggest that in many Indigenous cultures, Elders have a vital role in the health promotion of their community. However, neither the role Elders play or desire to play, nor the reception of Elder involvement in sexual health education/HIV prevention for Indigenous youth has been explored in the literature. This paper discusses the experiences of Elders participating in a participatory filmmaking and HIV/AIDS prevention workshop for Indigenous youth.

4.3 HIV/AIDS prevention and Indigenous youth

In addition to addressing colonization, "Wise Practices"²³ for HIV/AIDS education with Indigenous youth also indicate that arts-based strategies are a good way of engaging youth in HIV/AIDS prevention. Arts-based initiatives have emerged as engaging, empowering, and promising strategies for HIV/AIDS education and prevention with Indigenous youth (Flicker et al., 2014; Ricci et al., 2009). Flicker and colleagues (2014) argue that arts-based approaches can also be used as a decolonizing strategy within research. They explain that "arts-based approaches typically offer participants an opportunity to: participate equally in the decision-making process; learn and share new

²³ The term "Wise Practice" has been adopted by some in this field including the Canadian Aboriginal AIDS Network as they feel this term is more culturally relevant than "best, good, or promising practices. The premise is that wisdom is knowledge put to use" (Barlow et al., 2008, p.12).

skills; create counter-narratives that make visible previously hidden or silenced aspects of their identity or experience; and build on or reclaim their cultural identities or cultural practices” (p.19).

4.4 Methods

This community-based research study was undertaken as a partnership between me (a PhD student) and the HIV/AIDS Labrador Project based in Happy Valley-Goose Bay, Labrador. This study was informed by the principles of ownership, control, access and possession (OCAP®²⁴). The development of our arts-based HIV/AIDS education workshop was guided by the HIV/AIDS program coordinator, the HIV/AIDS Project Advisory Committee, discussions with community youth and other stakeholders and a review of the literature. We aimed for this workshop to be strengths-based, culturally-relevant, educational, and engaging. The type of arts was decided by informal consultations with youth that were held by youth group coordinators and arranged by research partners. Youth were asked to rank their interest in different types of arts including painting, hip hop, filmmaking, carving and drumming, and were invited to add their own suggestions. The youth were predominantly interested in learning about filmmaking; therefore, we developed a participatory filmmaking and HIV/AIDS education workshop. We hired film facilitators who could teach youth how to make their own films. As part of our desire for a culturally-safe environment and following the “Wise Practices” for HIV/AIDS prevention with Indigenous youth, we invited Elders to

²⁴ OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). www.FNIGC.ca/OCAP.

participate in the workshop (Flicker et al., 2008; Hampton et al., 2004; Rink, Montgomery-Anderson, & Anastario, 2014; Smillie-Adjarkwa et al., 2013).

4.4.1 The workshop

Eleven self-identifying Indigenous youth between the ages of eleven to seventeen participated in the workshop. The workshop included a one to two-hour session with an Indigenous educator from Healing our Nations, an Indigenous HIV/AIDS education organization based in Atlantic Canada. The rest of the time at the workshop was spent learning filmmaking skills, making films, playing games, participating in sharing circles, and sharing meals and snacks.

4.4.2 How did Elders come to be involved with the workshop?

Elders were invited to attend the workshop by an Elder on the HIV/AIDS Labrador Project Advisory Committee. The role Elders were to play in the workshop was fairly flexible. They were asked to participate in the workshop, to be there as knowledge keepers, to guide and support our gathering, and to build relationships with the youth participants. Five Elders from the various groups of Labrador Indigenous Peoples (that is, members of Nunatsiavut, NunatuKavut, and Innu Nation) in Labrador participated in the workshop and received an honorarium for their participation.

During the first evening of the workshop, one of the Elders approached me and indicated that the Elders were interested in making a film as well. The Elders chose what to make their film on through discussions with each other. They directed its creation, did preliminary editing, and made an editing plan for the final edits on their film together. Additionally, they involved one of the youth in their film. The youth took the role of the

‘interviewer,’ asking what the Elders learned about sexual health when they were growing up, what they learned about sexual health and HIV through our workshop, and why they thought it was important for the Elders to be part of youth education. This resulted in the creation of the film, “Condom in Grandma’s Bag.”

Informed consent was obtained from each Elder prior to data collection. Ethics review approval was granted by the Newfoundland and Labrador provincial Health Research Ethics Board (NL HREB) and NunatuKavut’s Research Advisory Committee. Information about this study was given to Nunatsiavut throughout the research process.²⁵

Approximately two weeks after the workshop, the Elders were invited to be interviewed. All but one of the participants were interviewed about their experiences at the workshop. The interviews ranged in length from 30 to 90 minutes and were digitally recorded and transcribed in full. Content analysis was used to identify themes emerging from the interview transcripts and the Elders’ film (Hsieh & Shannon, 2005).

4.5 Findings

Several themes and subthemes regarding the Elders’ experience at the HIV/AIDS education workshop emerged from the data. The overarching themes included comfortable engagement, the Elders co-creating a learning environment, and “closing the gap”: building relationships between youth and Elders. These themes and their subthemes will be discussed in the following pages.

²⁵ Nunatsiavut’s research review board only reviews research conducted on Nunatsiavut lands. The Innu Nation had no official research ethics process at the time of this research.

4.5.1 Comfortable engagement

An overarching theme that emerged from the data was that the Elders found the process of participatory filmmaking allowed for their “comfortable” engagement in the workshop. Subthemes emerging from this data include that the Elders expressed some initial hesitation to participate and that they developed comfortable engagement through the process of participatory filmmaking. These subthemes will be discussed below.

4.5.1.1 Initial hesitation

The Elders did not come to the workshop with the intention of making a film or partaking in an HIV/AIDS education session. In fact, several Elders expressed some initial hesitation to participation. Their hesitation was related to their lack of experience making films, never having participated in an HIV education workshop, and the involvement of outsiders to the community in the workshop.

One Elder identified his hesitation as being related to making films, something he had never done before:

Well, I was a bit worried, I thought maybe, you know, that I have never been involved in films like this before...but I did feel that there wouldn't be a problem.

We went at it. We just started going and planned what we were going to do.

Another Elder had some reservations as he had never been to an HIV workshop before:

Well, I didn't know exactly what because I didn't go to a workshop on HIV/AIDS before and I didn't know, I didn't know I could learn quite a lot from the...or whatever, the presentation so I didn't really know what to expect but I was

looking forward to working with the, there was young people involved there and I wanted to work with the young people.

A third Elder expressed some hesitation resulting from the involvement of ‘outsiders’ to the community. He stated,

Actually, because you were involving these people from [the film facilitators], I didn’t know what to expect, you know. But I was really, really, I hate to say the word pleased because it is so, but just, there has got to be a better word than that but it was easy, easy flow, I think, a good interaction.

Although several Elders identified some initial hesitation to participation, they also all stated that they found the workshop to be a very positive experience.

4.5.1.2 Developing “comfortable” engagement

Through participatory filmmaking, the Elders co-created an environment in which they were comfortable participating. They described their participation in the workshop as “comfortable.” They discussed feeling comfortable talking about HIV prevention, sexual health, sexual relationships, alcohol and other drug use with each other and with the youth. They also described feeling comfortable with the technology and being on camera. Factors that made their participation comfortable included working with youth, sharing with peers, connecting to traditional culture, feeling ownership and control, and working with an Indigenous HIV/AIDS educator.

4.5.1.3 Comfortable because they were working with youth

One Elder described feeling comfortable participating in this HIV/AIDS education and participatory filmmaking workshop because a youth was interviewing the

Elders in their film. He felt that this put the Elders at ease. He also felt very strongly about this youth/Elder interaction, stating that this process should be made note of for future workshops. He stated,

Well, because of the age of the camera operator, and just the rapport that people had with him, just natural, there was no, I mean I wasn't even, I never thought about being in front of the camera, the lens, stuff like that. I just talked to the people at the table and it was an easy thing to do, you know, so I think there may be lessons to learn from the way that the interview was conducted and by who and things like that. That is something to take notice of.

Likewise, another Elder explained a similar sentiment:

When the Elders talked, they didn't see, they didn't pay any attention to the camera and one of the good things, I thought anyway which made it relaxing, good, a bit more than normal, eh, was the young boy operating the camera. He was only about 10 or 11. He is a real nice boy, everybody like him, you know, so it wasn't like they were being interview by CBC or something like that so, easier way to do things, which is good. It was a really, that was a good idea to do that.

4.5.1.4 Comfortable because they were sharing with peers

In addition to the comfort created by the Elders and youth working together, the Elders also identified feeling comfortable participating in the workshop because they were speaking with their peers. For instance, one Elder stated that her comfortable engagement developed in part due to the fact she was sharing her knowledge about sexual health and HIV with her peers and learning from them in return:

Yeah, we were just comfortable. We just relaxed and we talked and we laughed and laughed about our own things, how we felt about what we saw or heard, because we weren't shown, we just heard about it. So it is better to see it, to be shown, that this film was and using film and then to show it, that we can talk about, and you can see in the film that we were relaxed you know. There was no prompting.

4.5.1.5 Comfortable because of the presence of traditional items

Another Elder indicated that she felt comfortable participating in part due to the traditional items that were in their film and surrounded them during their discussions. She felt these items created comfort as the Elders could connect with the youth by teaching the youth about the items and their culture:

I: So what else made it comfortable?

P: The crafts and that which we are used to seeing and which we were used to, which [participant's name] talked about his things and whatever we brought.

What did you bring [said to another Elder]? Whip?²⁶

P2: I brought the whip and

P: Yeah, so these things are familiar to us and we could tell the youth about them.

4.5.1.6 Comfortable because the Elders felt like they had control/ownership

The Elders felt they had control and ownership over their experience at the workshop, their film, and how they participated. Elders described the process as being

²⁶ Sealskin whip traditionally used for dogsledding.

very natural, which allowed them to feel comfortable participating. Additionally, they described feeling like they were free to explore any topics they would like:

I don't think there was any planning, just a natural, people started talking about things they were interested in and wanting to explore, in my opinion, more the subject matter you know, I think it was a natural evolution there, and there was no plan, there was no script, nothing like that. It was just a good dialogue with the people, as simple as that.

4.5.1.7 Comfortable sharing and learning with Indigenous HIV/AIDS educator

Although not part of the initial plan for the workshop, the Elders participated in an HIV education session with an educator from an Indigenous HIV/AIDS education organization once the workshop began. One of the Elders suggested they were particularly interested in this session because the educator was Indigenous

[The Elders'] interest was sparked, one of the things about [the HIV educator], she is native too, which that was a plus, you know, which made it easier for the Elders to connect with her...better than having some white nurse there, or doctor.

Overall, the Elders felt that their participation in the workshop was very 'comfortable.'

Their comfortable engagement developed from working with youth from their communities, sharing with their peers, having control over the process and their engagement and working with an Indigenous HIV/AIDS educator.

4.5.2 Elders co-created the learning environment

In addition to piquing their interest, this participatory filmmaking and HIV/AIDS education workshop allowed for the co-creation of an environment in which the Elders

felt comfortable talking about issues that may have been considered taboo, including HIV/AIDS, sexual health and relationships, and drug use. Additionally, the Elders felt comfortable talking about these issues not only among themselves but in an intergenerational dialogue between youth, Elders, and facilitators.

4.5.2.1 Knowledge Gaps

Through their participation in this workshop, the Elders identified that they had knowledge gaps related to HIV/AIDS prevention and sexual health; they identified that they require education around HIV and sexual health in order to be able to support and educate youth in their communities; they found the workshop to be educational for themselves regarding HIV/AIDS; and they learned filmmaking skills.

4.5.2.1.1 HIV/AIDS and sexual health knowledge gaps

The Elders identified that they had knowledge gaps with regard to HIV/AIDS prevention and sexual health through the process of making a film. One reason they felt they had knowledge gaps was that they were not provided with much information about sexual health when they were growing up. In fact, the Elders felt talking about anything to do with sexual health was taboo when they were growing up:

In our times we weren't allowed to hear anything, so for the longest time I couldn't speak about anything sexually or diseases or anything because we had to keep quiet, you know, if somebody said somebody was pregnant, oh my goodness, that is not for you to talk about, that is not for your ears, you know, so, people are more open [than] they use to be. When you grow up in the village and you are growing up in a religion or not only that religion but at those time we

couldn't because we were in a small village and mostly [Indigenous group] and these outside people were coming in and telling us this [...] and it was terrible to be talking about someone going to have a baby or someone whatever else, or had a disease that you just shut up, you clammed up so you couldn't talk about anything. So we kept all those year and even until we were married, 'oh, I didn't know that, you know, I didn't know that, I didn't know where a baby came from.

In their film "Condom in Grandma's Bag", the Elders state that they were not taught about HIV/AIDS growing up because it was not yet discovered. However, they also shared that they were not taught about sexual health when they were growing up. At the same time, they discussed how this lack of knowledge led to the development of stigma related to sexually transmitted infections. Several Elders expressed that they had no knowledge about STIs and their transmission, yet they were terrified of catching one from visitors. The Elders discussed this lack of knowledge in their film:

P: Well, we wasn't taught too much about HIV and that because we didn't, I never knew nothing about it even after I was an adult.

P2: We didn't know nothing about HIV back then because it wasn't around

P3: HIV only started coming around when people started travelling

P4: Travelling from outside the

P: Even the sexual relationship wasn't talked about.

P4: Nope we wouldn't.

P2: Oh no.

P4: We never had any sex education from our parents, eh?

P3: We were told that babies came from stumps, rotten stumps.

Other Elders: Yeah. Yeah.

P3: That is the education we had. As I said earlier, when I was growing up we didn't even know what VD was. Everybody was talking about VD and I didn't know what it was. All I knew was that it was something bad we were going to catch.

Through the process of sharing stories as part of the participatory filmmaking process, the Elders realized they had not received appropriate/enough information when they were growing up. As previously stated, this sentiment was reiterated in interviews conducted with the Elders.

The Elders felt that their peers in the community also had knowledge gaps related to sexual health and HIV and suggested that others would also benefit from participating in a workshop such as this one:

I'd recommend it to my friends. And why? Because if they don't have any idea what causes HIV or however, you, how people can catch it and all that, they don't know that, they would be the same as we are, we are in the dark, we didn't know anything about it, we didn't know.

4.5.2.1.2 Addressing the knowledge gaps

Some Elders were aware of their knowledge gaps prior to participation in the workshop. In fact, one Elder stated that she decided to attend the workshop "to learn more about what we didn't teach our children." Several Elders found participating in the filmmaking and HIV/AIDS education workshop to be an educational experience with

regard to increasing their knowledge about HIV/AIDS. One Elder stated, “I learned about HIV. I didn’t know much on HIV and things like that so it really helped me as well.”

Some of the knowledge gaps the Elders identified were around HIV/AIDS transmission and tools for preventing transmission.

4.5.2.1.3 Transmission

Elders commented that they increased their knowledge with relation to how HIV is transmitted: “I thought HIV was, you could get it just through sexual, you know, like intercourse or something, but it is not, it is [also] through drugs and needles and stuff like that.”

Several Elders commented that they were not aware that breast milk can contain the HIV virus. For instance, one Elder stated

I didn’t know how you caught HIV before, because at the film, I learned the baby’s milk too. You can get, babies can get it from their mothers through the milk and it was something I didn’t know about...sexual contact with somebody without protection.

In their film, the Elders also discussed learning that HIV can be in breastmilk and therefore is a pathway for mother-to-child transmission:

P: The baby’s milk.

P2: Yeah, that surprised me yesterday, the baby’s milk.

P: The baby, you could give it to the baby because the milk, from the breastfeeding.

Similarly, another Elder said that “the other surprising thing to me was that the, how you caught HIV like, I didn’t know, I always thought it was through gay men, you know, and that, it is not, you can get it through needles or whatever, so that was a surprise for me.”

4.5.2.1.4 HIV Prevention

In addition to methods of transmission of HIV, the Elders also found that they learned more about tools for HIV prevention. Each Elder was given a bag by the HIV/AIDS educator that included pamphlets, male and female condoms, and other items. One Elder stated he learned about “the tools which were used by the females and males so they wouldn’t contract...the disease.” Another Elder stated,

In that bag of items, the condoms and the items there, there are items there that I didn’t know about, that you could use for sexual educations, there was modern stuff there, I’d never saw before. I saw the condom when I was growing up, but that is about it. I didn’t know about other items that were there at the workshop. Several of the Elders commented on how they were not previously familiar with items such as the female condom: “It was always the male condom that was always out anyway, but females didn’t seem to have any sort of tools that I know about, I was really surprised.”

Several Elders also commented on how it was beneficial to their learning that the HIV educator took items such as the male and female condoms out of their packaging, passed them around, and explained how they were used. One of the Elders commented that this was the first time she had attended a workshop where these types of items were not immediately stashed out of sight. She stated,

That they can have these tools given out, like when we go to meetings or workshops, especially when...given these, but most of the times we don't look at the bag, we just shove it. But it was interesting to have them explained to us.

Another Elder agreed:

When we go to meetings, they just gave us, pack the bag up, but they don't explain what is in the bag, where [the HIV educator] took it out and showed us what they were for, how they were used...and if we had a question she answered it. That was good.

4.5.2.1.5 Beyond knowledge

In addition to gaining knowledge related to HIV/AIDS, some Elders expressed that they felt they gained skills. One Elder stated that participating in the workshop gave him both the knowledge and the confidence to talk about HIV/AIDS and sexual health in other settings, such as a meeting in the community:

If we were ever asked to a meeting such as that, at least we would have an idea, like we were there and really we didn't know anything about HIV, like we were telling you, and if we had had something like that, we should have had some idea to be able to talk about it.

Another Elder described how this HIV education workshop built their capacity to educate and support youth specifically. One Elder reported that "We can talk to the youth about diseases like that, that were contagious without feeling ashamed or shy because some parents can't talk with their children." They also saw the ability to educate and support youth with regard to HIV and sexual health as having other benefits. As one

Elder said, “if you can talk about that to young people, there are other things that depresses them and [they] do not feel well about, you could be able to talk with them about that too.”

4.5.2.2 The Elders learned by having discussions with their peers

When asked how the Elders learned by making a film, two Elders responded by saying that they found the chance to share their experiences with their peers to be enlightening:

P: [We learned] because we were talking to people.

P2: Yeah, I learned lots more.

Another Elder stated that she found some of her peers to have relatable ways of explaining and talking about these issues. She found it beneficial to talk with and learn from them. She stated, “[Participant’s name] really impressed me because she has a way of explain things, so do [Participant’s name] in his way, and it was, it was really good.”

One of the reasons some Elders found the opportunity to speak with their peers enlightening was because of the similarity of their experiences. Although they grew up in different communities in Labrador and were from different Indigenous groups, the Elders found that many of their experiences were similar with regard to the lack of information about sexual health and STBBIs. For instance, one Elder described learning that other Elders had also washed their hands to prevent contracting STBBIs, however, she also stated that she did not know how STBBIs were spread.

Because I didn't know like other people might have the same feelings we did, that we would wash our hands, you know to know that [participant's name] would wash his hands, and I washed everything.

Similarly, another Elder stated that she learned about the similarities between other Elders' experiences and her own through the discussions they had at the workshop:

P: I think it was because I talked with the other Elders and although we were pretty much on the same lines...Labrador, wasn't very well educated on HIV/AIDS so we did learn, I learned about the film and the workshop

I: Is that because you had discussions with each other about...?

P: Yeah, that's right, discussed

I: Your stories?

P: Yeah, like different northern Labrador and southern Labrador and of course central were involved. Because in Northern Labrador it is a little different there, a little farther away, and southern Labrador is into the different section and each section learns a bit from each other.

Learning that other Elders had had similar experiences, including the lack of education about sexual health, contributed to the comfortable, educational discussion between the Elders.

4.5.3 “Closing the Gap”: Building relationships between youth and Elders

The Elders had varying levels of connection to youth. Some felt like they did not have much contact with younger generations and others were very involved in the lives of their grandchildren, nieces and nephews, and youth in their community. However, all the

Elders interviewed felt they developed relationships with youth as barriers were broken down between generations at this participatory filmmaking and HIV/AIDS education workshop.

4.5.3.1 Gap between Elders and youth

Some Elders identified a lack of relationships between Elders and younger generations in their communities. For instance, one Elder expressed her feeling that youth are unaware that Elders are interested in connecting with them. She explained that she did not “think the youth sometimes realize that we have feelings and that we can, we can talk about anything.” Another Elder stated that she has few opportunities in her community for connecting with youth. She explained that,

As you get older, it is harder to talk with youth and communicate with them, so when they become teenagers, or 13 or even 11 or 12, they got their own friends so of course it is going to minimize them being with their grandparents, and we missed him, we miss them, you know, we miss our grandchildren, and now I wonder, how can we do that, you know, get together with them.

Additionally, she felt it was important for youth and Elders to connect. She stated this connection was important “because some may not have grandparents or someone to guide them or to look up to and make the parents feel that it is important that the youth and even us seniors have a nice feeling about each other.” Another Elder felt that there was a gap between youth and Elders she felt that they were often not included in programming together. She expressed that “we always seem to be left out. It is either the youth or the seniors who are left out; [the age groups] in between have all kinds of [programs].”

4.5.3.2 Loss of culture

The Elders felt that the gap between youth and Elders has resulted in a loss of culture and traditional social structures. One Elder suggested that the younger generations are not connected to their traditions. He explained that, “Some of the young people, I guess they have lost their culture, much of their heritage and culture.” Another Elder stated that

A lot of our people are losing our cultural heritage it seems, it is a shame though, I would like to see more people try to go back to the traditional ways more, you can’t go back entirely but you can never forget where you came from, traditional ways you know, it might help our people and the problems as I say, you know, to go back more to the traditional ways of our people.

4.5.3.3 Breaking down barriers

The Elders also identified that the workshop helped break down some of their assumptions about youth. One Elder stated that she learned that

Youth can be patient too...because you hear so much on the radio, TV and then town gossip: this person is in trouble, this person is in trouble. But there are some students who are willing to listen and have interest too. And they are willing to listen to seniors if we let them and they let us.

4.5.3.4 Elders have a role in the education of youth

Interacting with youth was a motivation for Elders to participate in the workshop. One Elder stated that she “was looking forward to working with the, there was young people involved there and I wanted to work with the young people, you know, that way.”

One Elder stated that he was motivated to participate in the workshop because it was an intergenerational opportunity and he felt that as an Elder he should be involved in educating the youth: “Well, I thought that we were helping our people to educate our people and youth about the traditional ways.” Another Elder explained that part of his role as an Elder is to connect with and educate youth

Maybe they could learn a bit from the Elders. I know our Elders are just too happy to work with the young people and got to educate them on the years gone by, like when you are Elder I feel that you almost, like you work in two different worlds, like when I grew up it was a very different world back then, like I mean to the modern world, and it is a very different situation today.

To further this, he explained that “We got to educate our people, how we lived years ago, the traditional way of our people.” His reasons for participating in the workshop were related to his desire to increase his knowledge about HIV, to connect with youth and educate them on traditional ways, and to offer an Elder’s perspective at the workshop:

Well, I wanted to bring out the, to learn something about AIDS and as well put it forward the Elders perspective, I guess, from like back over the years, like we lived in a different world back then, and I wanted to maybe compared with today’s modern way of life, I guess, that is one thing, And to kind of educate the children and public how we lived back 60, 70 years ago.

4.5.3.4.1 Desire to educate youth about HIV

The Elders expressed that they had an obligation to learn about HIV so that they could provide knowledge to youth and others in their community. Some Elders expressed

that they felt they had roles as educators for youth in the community. Through participation, several of the Elders identified that their role as educators included being able to provide youth with knowledge and support on topics such as HIV/AIDS, sexual health, drug use, and other related topics.

The Elders gained the knowledge and the desire to educate youth through their participation in this workshop. For instance, one Elder felt like he had learned a lot about HIV/AIDS and sexual health, and he was interested in educating youth about what he had learned. He stated, “I have learned a lot in the last while, I have got some, I have gained some knowledge that I could pass along to the youth.”

Some Elders expressed that their relationships with youth in their community as care givers or “knowledge keepers” meant that they could provide youth with information about sexual health and HIV/AIDS. One Elder recounted a story in their film in which she identified how her participation in this workshop created dialogue about sexual health and condoms with her granddaughter:

P: You know those packages that they gave us yesterday?

P2: Mmhmm.

P: The little plastic?

P2: Yep.

P: I had one in my, in my bag and my granddaughter is fifteen and I think she went to look for something in there and she came over to me yesterday, last night put the hand like this [behind her back], “Grandma, what are you doing?” I said, “What do you mean what am I doing?” “What’s this?” [and she] h[e]ld the little

bag where the condoms were. [Laughter] I said, “That’s where I’ve been, I have been up to the workshop for HIV.”

This story suggests that the granddaughter was comfortable communicating with her grandmother about the condoms she found in her purse and demonstrates that Elders have opportunities to provide support and knowledge about sexual health and HIV.

4.5.3.5 Teaching Culture

The Elders found the workshop to be an opportunity to teach youth about their culture, heritage, and history. For instance, one Elder explained:

I think I liked it where [Participant’s name] was showing how to use the whip, when we went outside and [Participant’s name] showed the youth like, snowshoes and I think that was nice for them to see, yeah, for the youth to see.

The Elders felt that the workshop broke down barriers both between the Elders and youth, and also between different cultural groups. One Elder felt that it was powerful to have representation from the three distinct Indigenous groups in Labrador at the table. He felt that this was an important gesture considering the segregation between Indigenous groups in Labrador:

It was a really, that was a good idea to do that. Sitting at the table you can see the three ethnic groups were there together, and all would comment, just, and that is a good thing because in my experience, in my life has been the provincial government in particular have adopted the philosophy of divide and conquer in Labrador. They have got three distinct groups, support them all and they promote them all and all they are doing is just pit them one against the other. So when I

saw the three groups together, with a common theme, I thought that was really good. So those are things that impressed me.

4.5.3.6 Building relationships between Elders and youth

This participatory filmmaking workshop allowed the Elders to co-create an environment in which barriers were broken down between generations. The Elders felt they had an opportunity to build relationships with youth through this participatory filmmaking and HIV/AIDS education workshop, as one Elder indicated “there is a gap, but it wasn’t the gap, if there was a gap that, that week, it was closed because I got to appreciate them more, and hopefully they got to appreciate us.” Another Elder felt that the only way that “the gap” between youth and Elders would be closed is through opportunities to connect such as this one:

I think it is closing that gap that everyone is talking about. Closing that gap between young people and the Elders and it is going to happen the more workshop or meetings I have with youth and Elders. That is going to close that gap up, yeah.

Another Elder enjoyed getting to know the youth. He explained: “We talked about HIV, I thought it mostly would be all on that, but it was fun to have, to sit with the youth and do the little games we done with them, to get to know them.” Similarly, another Elder stated:

I think we got to understand each other better...the youth and us, seniors, I got to understand the youth more because like, I was saying earlier, so many times we think that all they do is watch TV, play games, whatever is going on the Internet

and that, but when given a chance, youth have other interest, but they are not always given that chance.

Another Elder stated, “Well I was very happy to see how everything worked. Like I said earlier, I think it built up a relationship with the youth and Elders, you know, and I felt good about the workshop, you know.” Similarly, another Elder explained, “Yeah, I thought we kind of developed a relationship with some of the younger people, I think there should be more of this going on.”

4.5.3.6.1 Relationships beyond the workshop

The Elders felt that the relationships they developed with youth participants went beyond a workshop atmosphere. Some of the Elders have had continued contact with the youth they met at the workshop. For instance, one Elder indicated, “And now when I see them in town it is good to say hi to them or hello...if we are out and about and we see them, we will talk to them, yeah.”

4.5.3.6.2 Making a film gave the Elders a way to connect with youth beyond the workshop

In addition to developing relationships beyond the workshop with the youth who were present, the Elders felt making their film was a way to connect with and educate youth who did not attend the workshop. The Elders all agreed that the intended audience for their film was Indigenous youth. One Elder stated, “Well, I guess it was an aware thing, and I think [we can use the film] to make young people aware of the disease and how to protect themselves and how they can help other youth people with HIV or whatever.” Another stated, “I think these films will be well received.” Another stated, “I

am very happy because I think it is great if this movie, if these films start conversations with people and you can use them as a way to talk.” He stated, with regard to their film, “I don’t think it should be kept a secret, maybe we educate some of the people in the traditional ways back over the years. I would like to see everybody see it or take a look at it.”

Some of the Elders felt that making films was a good way to reach out to broader audiences. The Elders felt like they could educate and inspire youth through the creation of their film and that the films could have an impact outside the workshop context. One Elder stated, “Well, maybe the people will look at the film, be more interested in watching it, and see what on the film [...] I guess, give them more interest, see what’s going on, you know.”

Another Elder identified their film as a great way to start conversations. He stated, “I am very happy because I think it is great if this movie, if these films start conversations with people and you can use them as a way to talk.”

4.5.3.7 Acceptability of Youth and Elders together

The Elders felt that it was acceptable to include both youth and Elders in this participatory filmmaking and HIV/AIDS education workshop. One Elder stated that he had participated in workshops in the past that brought together youth and Elders and that he felt that involving youth and Elders in this workshop was a good idea:

Oh that is a good idea. Definitely a really good idea. I have been involved in that kind of thing in the past, not with AIDS but just general information and support sessions, you know....I think it is a real good idea... we had a workshop at [local

college] with people from all over the place, and Elders and youth. The interaction was tremendous there, tremendous, same with the HIV/AIDS. The interaction there was good too.

Likewise, another Elder agreed and furthered this sentiment by stating that filmmaking offered something promising for building relationships between youth and Elders, and for engaging in discussion of potentially sensitive topics such as HIV prevention, sexual health, and drug use:

I would recommend [this workshop] too, to show them that youth and seniors can communicate. Because everyone is trying to help the youth these days, and they have a sort of difficult time trying to find seniors who can talk to them and by doing a film with them is more comfortable because they are always comfortable, it was relaxing and comfortable...We didn't shut up, you know. We kept talking all the time. Because there is always a pause sometimes when people talk about things they are not comfortable with, 'oh my goodness, I can't talk about that,' you know, I think too, these days are more informative.

The Elders felt inspired by the youth. They felt like this workshop gave an opportunity for reciprocal learning:

We enjoyed working with the youth, they showed some things. The cameras were real good things to learn from but I would like to have more lessons, you know. That is a really good way to do it, it is not boring with the youth, they are young and they are vibrant, they give you ideas.

Overall, the Elders enjoyed found this workshop a good way to engage with community youth. One Elder expressed her desire to engage with youth stating, “Just inviting [Elders] to come watch is not the same as doing something with them. Do something with them!”

4.6 Discussion

This is the first study to look at the experiences of Elders at a participatory filmmaking and HIV/AIDS education workshop for Indigenous youth. Overall, the findings suggest that participatory filmmaking is an engaging and acceptable way for Elders to participate in HIV/AIDS education with Indigenous youth.

4.6.1 Comfortable engagement - decolonizing strategy

An overarching theme that emerged from the data is that the Elders found that the context and process of the workshop comfortably engaged them in participatory filmmaking and in HIV/AIDS education and prevention within an intergenerational environment. The history of research done *on* Indigenous people, with or without appropriate consent, has resulted in many Indigenous people (including in Labrador) being skeptical and wary of research and outside researchers coming into their communities (Brunger & Bull, 2011; Kovach, 2009; Smith, 1999). Comfortable engagement in this research and workshop is part of and indicative of a decolonizing approach.

The Elders identified several factors as contributing to their comfortable engagement in the workshop. These factors include working with youth, sharing with peers, presence of traditional items, ownership/control of their experience, and sharing

and learning with the Indigenous HIV/AIDS educator. Many of the factors that the Elders identified are similar to the “Wise Practices” recommended for youth HIV/AIDS prevention and education. For instance, Ricci and colleagues (2008) identify peer-based, culturally sensitive and decolonizing approaches, addressing the impacts of colonization, attending to diversity, addressing stigma, and arts-based and harm reduction approaches as the best ways of engaging in HIV/AIDS prevention with Indigenous youth.

One of the factors identified by the Elders as contributing to their “comfortable” engagement was that they felt like they had control over their participation in the workshop: they asked to participate in the HIV/AIDS education session with the Indigenous educator, they identified an interest in making their own film, and they felt like they had control throughout the process of filmmaking. These findings suggest that the workshop succeeded in engaging people in a way in which they could fully participate regardless of their level of knowledge. It also suggests that the semi-structured and flexible process of participatory filmmaking was successful as a decolonizing and engaging approach as the Elders felt they had control over their experiences and fully participated in the filmmaking. Additionally, the Elders felt empowered by the process of the participatory filmmaking and HIV/AIDS education workshop as they gained knowledge and confidence in their knowledge through participation in the workshop. This finding is in line with Flicker and colleagues’ (2014) sentiment that “decolonizing arts-based initiatives have as their goal the empowerment and affirmation of the participant” (p. 28). Likewise, Castleden and colleagues (2008) found that participants in their arts-based study felt that they had ownership over their creations and participation.

This finding is important as an indicator of doing research “in a good way” as there is an atrocious history of doing research *on* Indigenous communities and people to the benefits of colonial powers.

The Elders also found the workshop to be a “comfortable” space to talk about sexual health with their peers, with the HIV/AIDS educator, and with the youth. This is a significant finding as there is a call for Elders to participate in HIV/AIDS prevention programming for Indigenous youth. This call comes from youth themselves, yet there is very little guidance available as to how to engage youth and Elders in HIV/AIDS education or other health promotion initiatives (Flicker et al., 2008; Smillie-Adwerka et al., 2013). Additionally, this finding is significant as Hampton and colleagues (2007) reported in a study of Elders’ views on youth sexual health education that Elders found talking about matters of sexual health to be very difficult. Contrastingly, this research study suggests that participatory filmmaking is a comfortable way to engage Elders in topics of sexual health and HIV/AIDS prevention.

4.6.2 Developing Critical Consciousness

This participatory filmmaking and HIV/AIDS education workshop was an empowering and transformative learning experience through which the Elders developed critical consciousness. Critical consciousness, a concept developed by Paulo Freire, is the ability to see the oppressive forces that govern one’s life and to take action against them (Freire, 1970). Freire’s pedagogy of the oppressed challenges traditional ways of teaching that assume learners are empty vessels waiting to be filled with knowledge by teachers/experts (Freire, 1970). Consistent with Freire’s pedagogy, several Elders

identified having the opportunity to talk with their peers, other Elders who grew up in Labrador, from different communities and different cultural backgrounds, to be one of the factors that made this workshop a valuable learning experience. The Elders found speaking with each other to be enlightening. Although they were from different communities, they realized they shared many similar experiences. For instance, the Elders were not aware of how similar their experiences were with regard to feeling like they had knowledge gaps about sexual health. Through these conversations, the Elders identified that the legacy of colonialism and influence of the Christian church had resulted in the loss of traditional ways and systems of passing on knowledge, ultimately resulting in the taboo of speaking about anything to do with sexual health, reproduction, or sexuality. Arts-based health promotion strategies are often linked to decolonizing arts-based practices and to Freire's concept of critical consciousness "which seeks to engage individuals in questioning of their historical-social situation" (Castleden et al., 2008, p.1395–6). This ability is critical in HIV/AIDS education and prevention with Indigenous people as the ongoing impacts of colonization have resulted in disparities in health and overrepresentation in the HIV/AIDS pandemic in Canada (Loppie Reading & Wien, 2009; PHAC, 2014).

4.6.3 Knowledge gaps

Through their participation in this participatory filmmaking and HIV/AIDS education workshop, the Elders identified that they had knowledge gaps with regard to sexual health. As stated, several Elders identified sexual health to be a very taboo topic while growing up and connected this to the impacts of colonialism, religion, and small-

town life. The Elders related the taboo nature of the topic to knowledge gaps in sexual health.

The finding that there is a knowledge gap resulting from the impacts of colonialism and religion has been discussed in relation to Indigenous peoples in other regions of Canada. However, most of this other research describes the perspectives of youth or other adults who feel Elders have knowledge gaps or find talking about sexual health to be taboo rather than the perspectives of Elders themselves. For instance, Rand (2014) found that Inuit women she interviewed felt Elders in their community did not discuss sexuality due to its taboo nature. Likewise, Smillie-Adjarkwa and colleagues (2013) reported that the Indigenous youth they interviewed felt Elders were too “ashamed to talk about sex due to Residential Schools and Christianity” (p.106). Rink and colleagues (2014) found that Indigenous parents in Greenland did not discuss or feel comfortable discussing sexual health or STIs with their children but also felt there was a role and a need for Elders to be included in sexual health education for youth in their communities. Danforth (2014) suggests that “historical trauma and colonialism have made it difficult for many Indigenous families and individuals to discuss sex and sexuality”. Similarly, Stern and Condon state that colonization “left parents and Elders (who were the primary educators of sexual and reproductive health in the past) feeling ill equipped to teach their children about sexual health” (Stern & Condon, 1995, as cited in Rand, 2014). The findings from this study are similar to these other findings; Elders participating in these studies identified a lack of knowledge and the taboo nature of the topic. However, it is important to note that through this process of participatory

filmmaking, Elders felt like a comfortable environment was created for these discussions both with each other and with youth participants. The findings suggest that participatory filmmaking is a successful way in which Elders and youth can discuss sexual health issues together.

4.6.4 Closing the Generation Gap

The environment co-created by the participants of this participatory filmmaking and HIV/AIDS education workshop allowed Elders to break down barriers and develop connections with youth. The Elders identified this workshop's approach as unique, involving both youth and Elders in HIV education together, and they found this opportunity for interaction beneficial.

The Elders participating in this workshop varied with regard to how much contact they had with younger generations in their community. Several felt like they did not have much contact with younger generations while others were involved in the lives of their grandchildren, nieces and nephews, and youth in their community. Although this was a short, one-off workshop, the finding that participatory filmmaking allowed for connections to be made between Elders and youth is relevant in terms of HIV/AIDS prevention, and wellbeing in general, as research suggests connection to culture and strengthening identity to have protective effects on health (Flicker et al., 2013; Chandler & Lalonde, 1998; Kirmayer, Simpson, & Cargo, 2003). Flicker and colleagues (2013) suggest, "Providing youth with opportunities to connect with the culture and elders/grandparents, learn and practice ceremonies, and explore traditional models of healing may improve health" (p. 8). Additionally, as well as being "knowledge and

culture keepers,” Elders in many communities are well positioned to provide guidance and support with regard to health and wellbeing as they are often caregivers for younger people, including their children and grandchildren, nieces and nephews, grandnieces, and grandnephews (Fuller-Thomson, 2005).

In a recent study on the connections between Elders and youth in a small Labrador community, Gabel, Pace, and Ryan (2016) found that Elders felt strong connections to the youth in their community. Perhaps one reason for the difference in connection between youth and Elders in those two communities is due to the size differences between the communities: Happy Valley-Goose Bay is considerably larger than the other community. St. Lewis has a general population of 210 people with 160 people (76.2%) identifying as Indigenous (Gabel, Pace, & Ryan 2016) whereas Happy Valley-Goose Bay has a population of 6408 people, with 2965 (46.3%) people identifying as Indigenous (Statistics Canada, 2017). Also, this other study was not approached from a HIV/AIDS prevention or sexual health education standpoint, which may have been a factor in how Elders perceived their connection to youth.

All the Elders in this study expressed an interest and duty to be educators and role models for youth and identified a need for education in order to do so. Other studies have found that Indigenous youth are interested in having Elders involved in sexual health education and HIV/AIDS prevention for youth. For instance, Flicker and colleagues (2008) found that the Indigenous youth they interviewed felt older people including Elders do not want to talk about HIV/AIDS; however, these youth felt Elders should be involved in HIV prevention for youth. Ultimately, building capacity with Elders and

including them in intergenerational programming will have an impact on Indigenous youth and HIV/AIDS prevention.

Participatory filmmaking in an HIV/AIDS education context allowed the Elders to connect with youth and build their capacity through education and empowerment. The findings from this study suggest that participatory filmmaking has the potential to be a comfortable, acceptable, and engaging strategy for HIV/AIDS education and prevention with Indigenous Elders and youth. These findings are similar to those of Fletcher and Mullett (2016) who report that their digital storytelling health promotion intervention also allowed for intergenerational dialogue and relationships to form between youth and Elders.

4.6.5 Beyond Indigenous HIV/AIDS prevention

According to Iseke and Moore (2011), “Indigenous digital storytelling and research are as much about the process of community relationships as they are about the development of digital products and research outcomes” (p. 19). This sentiment is shared by others who use arts-based methods in Indigenous health promotion initiatives (Flicker et al., 2014; Prentice, 2015). Similarly, the findings from this study suggest that the process of participatory filmmaking facilitated the development of relationships and connections between youth and Elders. These relationships and connections may have an impact not only on HIV/AIDS prevention but also on the general wellbeing of participants. For instance, cultural continuity, connection to culture, and identity are protective factors in the overall health of Indigenous people (Chandler & Lalonde, 1998). Cultural continuity is a determinant of Indigenous people’s health (Auger 2016; Loppie

Reading & Wien, 2009). For instance, Chandler and Lalonde (1998) found that suicide rates in Indigenous populations were associated with “a constellation of characteristics referred to as ‘cultural continuity’” (Loppie Reading and Wien, 2009, p. 21). Cultural continuity is described as cultural and social cohesion within a community and is linked to factors such as generational connectedness (Loppie Reading & Wien, 2009; Rand, 2014). The findings suggest participatory filmmaking was successful in building connections between Elders and youth. The findings also suggest that Elders felt that these connections could have an effect on many aspects of health and wellbeing, not just HIV/AIDS prevention. Hence, participatory filmmaking may be a useful approach for engagement in other types of health promotion initiatives such as mental health and suicide prevention where the connection to culture has a health promoting effect (Auger, 2016; Chandler & Lalonde, 1998; Jacono & Jacono, 2008).

Additionally, although STI rates are on the rise in older adults within the general population (CPHA, 2013), this did not come up in the discussions with the Elders who participated in the workshop. Rather, the Elders who participated felt that their role was to be knowledgeable about sexual health and to provide support and guidance to community youth. The Elder’s film, “Condom in Grandma’s Bag,” even positions the intended audience within its title. However, noting that the Elders found the opportunity to discuss issues of sexual health and HIV/AIDS prevention with their peers to be beneficial, there may be lessons to learn for health promotion initiatives with older adults.

4.7 Implications, Recommendations

For service providers and other researchers, this study's results suggest several areas for action:

- 1) Service providers and program developers should consider including youth and Elders together in HIV prevention and education initiatives.
- 2) Participatory arts-based strategies such as participatory filmmaking can allow for Elders to connect, share, and learn.
- 3) Elders find peer-learning opportunities to be beneficial.
- 4) Elders could be a beneficial resource as HIV/AIDS educators in their communities.
- 5) Service providers should consider developing more HIV/AIDS education and prevention programming for Elders.

4.8 Limitations

There are several limitations of this study. The findings of this study are highly community specific as the development of the workshop and the aspects of the workshop were led by research participants and community members. The Elders who participated in this study were recruited by one Elder on the HIV/AIDS Labrador Project Advisory Committee. The Elders in this study were very positive about using filmmaking in this context, this does not mean that Elders in other contexts would find participatory filmmaking a positive experience. Additionally, the duration of the workshop was relatively short, and the participants were interviewed only once – two weeks after the workshop.

4.9 Conclusion

Few HIV/AIDS education and prevention initiatives have included youth and Elders working together, and even fewer have used arts-based strategies. The findings of this study suggest that filmmaking is a promising decolonizing strategy for HIV/AIDS education and a platform for building relationships between youth and Elders. This study sought to involve Elders throughout both the research and health promotion workshop for Indigenous youth as a culturally appropriate approach recognizing the roles Elders play and could play in health promotion. The role of Elders participating in this workshop was not well-defined at the outset. However, the environment co-created by the Elders, youth participants, and facilitators in the context of participatory filmmaking resulted in comfortable engagement in both HIV/AIDS education and filmmaking. The use of participatory filmmaking was intended to provide a decolonizing and very flexible strategy for engagement that would allow for the voices of the participants to be heard. The findings demonstrate that involving Elders HIV/AIDS prevention programming with youth can be a very positive experience. These findings suggest that participatory filmmaking can be an excellent culturally appropriate, engaging strategy for HIV education. Further research into the use and reception of the films within the local community and greater community is required. Overall, this research contributes both to the emerging dialogue on the evaluation of arts-based HIV/AIDS education and prevention in Canada, and to developing practical resources for HIV/AIDS educators.

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5. Conclusion

My doctoral dissertation explored the use of participatory filmmaking as a strategy for HIV/AIDS education and prevention with Indigenous youth in Labrador. The impetus for this study was to address a research question brought forward by a community knowledge user/service provider and to address a gap in the literature around the assessment of arts-based HIV/AIDS prevention initiatives. This study is the first I am aware of to evaluate knowledge and attitude change among Indigenous youth engaging in participatory filmmaking as a strategy for HIV/AIDS prevention. It is also the first to include Indigenous youth and Elders together in a participatory filmmaking and HIV/AIDS education workshop and to explore their experiences in this context.

Each manuscript in this dissertation provides a different perspective through which to examine the use of an arts-based strategy in HIV/AIDS education for Indigenous youth. The first manuscript used a mixed methods approach to examine HIV/AIDS knowledge and attitude change in the youth participants after they attended the arts-based workshop. Analysis of the responses to the two questionnaires 18-item HIV-KQ (Carey & Schroder, 2002) and “Your Beliefs” attitude questionnaire (Popham et al., 1999)) showed significant improvements in the youth participants’ HIV/AIDS knowledge and attitudes after the workshop. The qualitative interview data are congruent with the quantitative data as analysis of the interviews indicated that HIV/AIDS knowledge and attitude levels improved after participation in the workshop. The qualitative analysis provided a more comprehensive understanding of the participants’ learning that emphasized what the youth learned, how they learned, how they

operationalized new knowledge, and how they related their learning to the participatory filmmaking workshop. This manuscript is one of the first to provide a mixed-methods analysis of the potential of an arts-based HIV/AIDS education intervention to influence knowledge and attitude change for Indigenous youth in Canada.

The second manuscript described the youth participants' experiences at the workshop to better understand how they learned and participated at the workshop. In order to explore if this method of engagement is engaging and can be fun, decolonizing, empowering, and educational, it is crucial to have an understanding of participants' experiences. Their experiences provided insight into how they engaged in arts-based HIV/AIDS education, how they perceived this arts-based approach, and how they learned in an arts-based workshop. Additionally, through the qualitative analysis and use of interview quotations, this manuscript allows for the participants' voices to be heard, to better understand their experiences.

The third manuscript explored the experiences of Indigenous Elders participating in an arts-based HIV/AIDS education workshop for Indigenous youth, which provided insight into the role Elders play and wish to play in HIV/AIDS education for Indigenous youth, and how participatory filmmaking can be a platform for these intergenerational interactions. In addition to these findings, this manuscript demonstrated the flexibility and emergent nature of CBR. The research question for this manuscript, investigating the Elders' experiences at the workshop, was not included at the outset of the project. Rather, it was added as Elders took an active role in the workshop. The findings presented in this manuscript also suggest that the method was decolonizing and the participants were

engaged and took ownership of this workshop and its process as they steered its implementation and tailored it to meet their needs.

Overall, the findings from these three manuscripts suggest that participatory filmmaking, an arts-based strategy for HIV/AIDS education and prevention with Indigenous youth, is very promising as an engaging, educational, and decolonizing approach. These manuscripts demonstrate the successes of this arts-based HIV/AIDS program. According to the pre- and posttest statistical analysis and qualitative interviews with youth, the participants learned; they were engaged; and they had fun. According to interviews with the youth and the Elders, the CBR process and the participatory filmmaking process were accessible and empowering. These findings are critical to developing effective, decolonizing, engaging, and appropriate HIV/AIDS prevention strategies for Indigenous youth, as improving knowledge and attitudes and the resulting reduction in stigma are essential factors (but not the only factors as one must also consider the other social ecological factors) for addressing the overrepresentation of Indigenous youth affected and infected by HIV/AIDS in Canada (Baral et al., 2013; Flicker et al., 2013; Flicker et al., 2014; Larkin et al., 2007). Additionally, these manuscripts contribute to the emerging dialogue on arts-based HIV/AIDS education and prevention in Canada by presenting participants' voices and evaluating an arts-based workshop, and to developing practical resources for HIV/AIDS educators (further discussed in the following sections).

While these manuscripts provide a snapshot of the experiences of participants in this arts-based workshop, they do not present detailed information on the process of the

workshop, or community-based research process, or on the films that were made during the workshop. I plan to discuss these issues in future papers, as they are beyond the scope of the core thesis research questions, which sought to evaluate knowledge and attitude change after participating in the workshop, as well as provide an in-depth analysis of participants' experiences using an arts-based strategy within an HIV/AIDS prevention context. However, I have included reflections on some of these issues in the sections that follow.

5.1 Implications of the research

There are several main implications of this research. This first is that it supports the notion that participatory filmmaking is a promising arts-based strategy for HIV/AIDS education with Indigenous youth (Fanian et al., 2015; Flicker et al., 2012, Mikhailovich & Arabena, 2005, Lys et al., 2016, Lys, Logie, & Okumu, 2018; Ricci et al., 2009). Similar to the findings of other studies that have explored the use of the arts in HIV/AIDS prevention for Indigenous youth (Flicker et al., 2013; Flicker et al., 2014; Lys et al., 2016; Lys et al., 2018; Lys, Logie, & Okumu, 2018), the participants in this workshop were engaged, learned, and had fun. However, this does not mean that all filmmaking workshops would be equally engaging, educational, or fun. The participatory nature and group nature of this workshop greatly contributed to the youth's experiences. A filmmaking workshop where youth made films individually, or a workshop that was less participatory, could have very different levels of engagement. Likewise, not all genres of the arts have the same impact on the participants. One could imagine that other types of

arts-based workshops could offer very different experiences for the participants resulting in different levels of impact.

A second implication of this research is that participatory filmmaking positions youth as educators. This finding is noteworthy as peer education is a “Wise Practice” for HIV/AIDS prevention both with Indigenous youth and in general (Lemieux, Fisher, & Pratto, 2008; Mikhailovich & Arabena, 2005; Ricci, Flicker, Jalon, Jackson, & Smillie-Adjarkwa, 2009; Vujcich, Thomas, Crawford, & Ward, 2018). Again, participatory filmmaking in groups as a strategy of engagement and education may possess unique qualities that contribute to the participants positioning themselves as educators. Other types of arts-based strategies may not elicit similar responses from the participants. This finding is important for program developers and service providers who require resources for developing peer educators.

A third implication of this research is that, as with other areas of health (such as mental health), Elders can play a role in HIV/AIDS education for Indigenous youth (Flicker et al., 2008; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007a; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007b; Smillie-Adjarkwa et al., 2013). Participatory filmmaking is one way to bring youth and Elders together to create intergenerational dialogue and build relationships between generations. Elders should be included in prevention efforts. The Elders in this study felt they have a role in youth sexual health education and HIV/AIDS prevention. The youth participants also found it appropriate and beneficial to have Elders participating in this workshop. In order to support Elders in this role, they should be included in HIV/AIDS prevention initiatives

for youth. As well, Elders may benefit from having HIV/AIDS education initiatives specifically for them to build their knowledge, confidence, and capacity to address these issues with youth.

Additionally, this study challenges some of the traditional didactic approaches to health promotion and sexual health programming that are passive, moralizing, fear-based, and potentially less effective (Beausoleil & Petherick, 2015; Flicker et al., 2013; Flicker et al., 2014; Lupton, 2015). Both the youth and Elders who participated in this workshop described their participation as “fun” and “educational.” These findings suggest that health promotion does not have to be anything less. Health promotion can be fun and engaging, as well as effective.

These findings from this study suggest numerous recommendations for service providers and other researchers. For instance, similar to other research findings and recommendations in the literature, service providers and program developers should consider bringing youth and Elders together in HIV prevention and education initiatives (Flicker et al., 2008; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007a; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007b; Healey, 2014; Smillie-Adjarkwa et al., 2013). Some studies have suggested that although Elders have a role in sexual health education with Indigenous youth, some Elders may find talking about sexual health to be difficult (Flicker et al., 2008; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007; Healey, 2014; Rand, 2016; Smillie-Adjarkwa et al., 2013). However, participatory arts-based strategies such as this participatory filmmaking workshop can allow for Elders and youth to connect, share, learn, and have fun while

discussing sexual health. Additionally, Elders could be a beneficial resource as HIV/AIDS educators in their communities (Flicker et al., 2008; Hampton, McKay-McNabb, Farrell Racette, & Byrd, 2007; Healey, 2014; Smillie-Adjarkwa et al., 2013). Service providers should consider developing more HIV/AIDS education and prevention programming for Elders. Finally, the participatory nature of filmmaking offered the youth and Elders an opportunity to express themselves and connect, which may have additional benefits on health and wellbeing (Fanian, 2015; Riecken et al., 2006). For instance, cultural continuity may increase youth resiliency and have health protective qualities in relation to suicide in Indigenous populations (Chandler & Lalonde, 1998; Chandler & Lalonde 2008).

5.2 Knowledge Sharing

As indicated in the Introduction, knowledge translation and knowledge sharing are often built into the process of CBR. In the case of my doctoral research, knowledge sharing opportunities were planned and occurred with the HIV/AIDS project Advisory Committee throughout the research process, as with many of the other stakeholders in this project. For instance, during the research process I gave presentations about HIV basics and HIV in Indigenous communities. As well, members of the Advisory Committee and other stakeholders were present at the community debut of the films, at a research conference in HV-GB, and at the Labrador Creative Arts Festival. On a community level, our debut of the films, and their presentation at the Labrador Creative Arts Festival, allowed for the initiation of an intergenerational dialogue on the research

topic and on HIV/AIDS within the community. Additionally, the films have been shown in community contexts including with the Seniors' Group at the LFC.

5.2.1 Impact Beyond Participants

The opportunity to share these films within the community and have their creators (the participants) present them was an asset of participatory filmmaking. Sharing these films with the participants' families, parents, siblings, aunts, uncles, grandparents, friends, and other community members has implications for public health. All of these people are now included as being part of this participatory filmmaking workshop on some level. This extended "intervention" requires further analysis in the future. Sharing the films with the larger community also allowed me to see the response to the youth's creations from the audience. For instance, at least three of the parents or guardians cried when they saw their child's film the first time. Many of the parents or guardians spoke about how proud they were of their children, and how surprised they were that their children were so engaged in the filmmaking process. Additionally, after the films were played at the LCAF in 2015 (eight months after the workshop), one of the parents or guardians approached me to say that her child had sparked a real friendship with one of the Elders from the workshop that has continued after the workshop.

Additionally, many of the findings arising from this research project have been reported back to the HIV/AIDS Labrador Project, its Advisory Committee, and the LFC. Findings from this research project have already been presented at national and international research conferences, community events, and to a variety of audiences

including Indigenous youth, knowledge users, policy makers, academics, and other stakeholders (see Appendix G).

5.3 Limitations

5.3.1 Sample characteristics and study design

One of the limitations of this study with regard to the evaluation of knowledge and attitude change is the sample characteristics. While the size of the group worked well for the purposes of making films, the small, self-selected nature of participants means that the data from the pretest and posttest is not generalizable. Additionally, knowledge and attitude change were only assessed over a very short time period. The findings of this study would be strengthened by providing an assessment of knowledge and attitude change over longer periods of time to assess whether knowledge and attitude changes were sustained. In addition to knowledge and attitude change, many studies also collect information about HIV/AIDS risk-related behaviours, because ultimately, program designers want to know if there is an increase in preventative behaviour, and link this to a reduction in HIV infection. We did not include an assessment of behaviour change related to HIV/AIDS infection, such as information about sexual activity or drug use, which may provide greater context to the study and needs of the population.

5.3.2 Addressing social and structural factors including colonization

Another limitation of this study is that the social and structural factors that increase risk of HIV infection among Indigenous people were not assessed. Other studies have examined how youth connect HIV prevention to concepts such as colonization and facilitated youth's engagement in this topic through the use of the arts (for instance see

Flicker et al., 2014). The intention of this study was not to examine the structural factors related to HIV infection in Indigenous communities, but to look at the use of an arts-based method of engagement and HIV prevention. As such, the youth participants in this study did not directly address colonization through their films, or in their interviews. On the other hand, the Elders who participated in this study did address some aspects of colonialism during the participation in the workshop. For instance, they framed their film, “Condom in Grandma’s Bag,” around questions including what they knew about HIV/AIDS in the past and what they know now. They also explored these questions in their interviews, as described in Chapter 4. They related the introduction of HIV and other STBBIs into their communities to people from away settling in their communities. Additionally, they related their lack of sexual health knowledge to the influence of the Christian church and break down of familial structures related to residential schooling. They also spoke about the resulting loss of connection between Elders and youth. Although the youth did not directly discuss social and structural factors related to HIV infection in Indigenous populations in their films or interviews, the workshop provided an opportunity to introduce them to concepts related to the impacts of colonization through the sharing with and learning from the Elders that took place each day, in addition to observing the Elders create their film. In this way, this participatory filmmaking workshop address aspects of colonialism by creating space for Elders to teach youth and for youth and Elders to build relationships.

5.3.3 Context specific study design

A further limitation of this study is that it is community specific. The study was developed through consultations with community members and research partners about the needs, interests, and resources in their community. Youth in this community were interested in learning how to make films. This does not mean that youth in other communities would find filmmaking an appropriate or enjoyable way to engage in an HIV prevention workshop. Additionally, the participants in this workshop found the intercultural opportunity to come together and share to be beneficial. As described in the introduction, the history of colonization, politics of Indigeneity, and the differing relationships between the groups of Indigenous People's in Labrador and the provincial and federal governments, as well as industry, may have created tensions between groups. Some of the Elders in this study commented on these tensions in their interviews. Both the youth and Elders spoke about enjoying the opportunity to learn and build relationships with people from other Indigenous groups. This finding is relevant to and situated within a Labrador context. Implementing a similar cross-cultural workshop in other areas may or may not be as well received or appropriate. It is my intention that this dissertation provides sufficient detail about the workshop and the context of this research so that readers may assess the usefulness and transferability of these findings to other contexts.

5.4 Further research

Discussions of transferability, evaluations of impact, as well as short- and long-term effects of arts-based health promotion programming and research are

underdeveloped (Boydell et al., 2012a). Much of the literature on arts-based health research focuses on the process and unique ethical issues rather than the artistic creations developed through the research process (Boydell et al., 2012a; Boydell et al., 2012b; Gubrium, Hill, & Flicker, 2014). Additionally, there continues to be a gap in the literature on how to evaluate the utility of arts-based health research creations, including whether these products are effective with new audiences. Further research into the use, impact, and reception of these films within the local community and greater community is required and could contribute to the emerging evaluative literature on arts-based HIV/AIDS education initiatives as well as on arts-based interventions more generally. The films created at this workshop are locally and culturally relevant materials that can be used as resources in HIV/AIDS education with other audiences. Additionally, the participants viewed their films as educational tools. I have had discussions with the various coordinators of the HIV/AIDS Labrador Project about their potential use in their school-based HIV/AIDS information sessions. Additionally, I have received many inquiries from knowledge users at conferences across Canada who would like to show these films in their communities.

This dissertation did not discuss the content of the films in depth, instead focusing on the experiences of the participants who made them and whether HIV/AIDS-related learning occurred. Future research could provide an analysis of the content of the films, as well as the use of participatory filmmaking as an arts-based data collection method.

Additionally, this study assessed knowledge and attitude change over a very short period of time (after three days for the questionnaires and two weeks for the interviews).

Future research should assess the longitudinal effects on knowledge and attitude change. Furthermore, future research could include an assessment of HIV-risk-related behaviour and behaviour change after participation in an arts-based initiative (for assessment of HIV-risk-related behaviour see Benni et al., 2016; Fisher, Fisher, Byran, & Misovich, 2002; Hoehn et al., 2016; Misovich, Fisher, & Fisher, 1998).

Many youth participating in this workshop saw their films as tools for peer education and viewed themselves as educators. Riecken and colleague's (2006) found that Indigenous youth participating in their film-based health and wellness initiative positioned themselves as educators through the creation of films, as well. Similarly, Flicker and colleagues (2017) describe digital storytelling as a successful strategy for leadership development with Indigenous youth in the context of HIV/AIDS prevention. This has not been explored in the context of participatory filmmaking as a strategy for HIV/AIDS education with Indigenous youth in Canada. As peer education continues to be described as a wise practice, further research is required to explore the use of participatory filmmaking as a peer education strategy in the context of HIV/AIDS education.

Another factor that should be considered in future research is a cost-benefit analysis of arts-based health promotion programs as arts-based programming can be very resource heavy (Boydell et al., 2012a; Clift, 2012). As stated, due to the turnover of staff at the HIV/AIDS Labrador project, we decided to hire film facilitators and have an educator from HON come to the community. The facilitators provided equipment and facilitation for our workshop; however, similar workshops could also be done using

easily accessible and relatively cheap (or free) video recording equipment and editing software. This would substantially reduce the costs of hosting this type of arts-based workshop. Additionally, costs could be reduced if facilitators were available in the community or if community members were trained to provide facilitation for future workshops.

5.5 Challenges

5.5.1 Staff turnover

I faced a number of challenges during this research study. One of the major challenges in this research was the high turnover of staff at the HIV/AIDS Labrador Project. While the initial impetus for the research came from the coordinator of the project, and she and I, in consultation with the Advisory Committee, conceptualized the overarching project, by the time we were able to implement the workshop she had resigned her position in order to pursue further education outside of the province. After her resignation, there were a number of coordinators hired by the LFC for this position. When we implemented our workshop, the coordinator had only been in the position for two weeks and had not yet received training. As stated in the previous section, for this reason, we opted to have an educator from Healing Our Nations deliver the HIV/AIDS education content for the workshop.

The high turnover in staff for this position raised many issues for me. For instance, this meant that much of the recruitment fell to me. As well, it meant that I had to make stronger connections with other stakeholders. For instance, one HIV/AIDS coordinator was supposed to deliver the survey investigating the youth's interest in types

of art to community youth, but she had vacated the position during that time period. Instead, I worked with community youth group leaders to deliver this survey at a number of sites and the new coordinator compiled the results.

Additionally, there were periods of time where I was unable to discuss the research project or ask the coordinator questions about the community as the position was either vacant or the new coordinator was just learning herself/himself. At some points, I was the person providing the coordinator with background information for the position, institutional history, contacts in the field, and information on HIV/AIDS and STBBI prevention. I was happy to do so, but also always cautious of overstepping my role.

This high turnover also raised some issues with regard to CBR. For instance, when partnering in a CBR research project, do you partner with a person, or the position, or the organization? Often times there are “champions” in communities who are interested in a research topic, see a need for research, and are willing to put in extra thought and time beyond the scope of their job description (Israel et al., 2006). However, these topics may not be the same for every coordinator that comes into the position. As discussed by Israel and colleagues (2006), this is not an uncommon challenge of CBR. Similarly, Minkler (2005) describes the constraints of community involvement as one of the challenges of CBR (see also Brunger & Wall, 2016). Minkler suggests that while researchers may have great intentions to involve community throughout the research project, this may break down during the research process.

5.5.2 Community participation

Over the course of my doctoral research, I found community involvement to be a challenge at various points. In many ways, the “community” shifted as the project developed. The project was initially conceptualized and developed with the HIV/AIDS Labrador Project Coordinator, the Project’s Advisory Committee, and the LFC. When the initial coordinator resigned, my relationship with the Advisory Committee shifted as I had initially relied on the coordinator to facilitate communication with the others. Once the workshop was underway, the “community” shifted again. The project then became guided by the research participants. Ideally, I would have liked to have the research participants co-analyse the research data through a participatory process. However, this did not happen due to funding, time, and access. On the other hand, one of the strengths of using participatory filmmaking in this workshop was that it allowed for the wider community to be included in knowledge translation activities as parents, grandparents, siblings, Elders, and other stakeholders attended the film debut event where the youth and Elders presented their films.

5.2.3. Financial challenges

A third challenge of this research was the associated costs. It was very expensive to run this workshop, to rent the space, buy the food, hire facilitators, and pay for travel. I incurred additional expenses with my numerous trips and extended stays in Labrador, which were required to meet with stakeholders, plan the workshop, and follow-up. I am very thankful for the funding I received as a doctoral student and the funding awarded to

the project. Without access to this funding, I would not have been able to do this research.

5.2.4 Other challenges

What feel like small challenges now (but which were not, in the moment) included a number of issues related to travel, communication, last-minutes cancellations, and weather. For instance, one challenge was dealing with flight cancellations for the film facilitators, both as they were on their way to the community and when they were leaving the community. Another challenge was that the week leading up to the workshop there was no internet in the community, as the cable had broken outside of town. This meant that it was extremely difficult to communicate with participants, research partners, institutions (ethics and university), and others while making the final plans for the workshop. A third challenge that arose on the first day of the workshop was that the principal of the school where we hosted the workshop emailed that morning to say that we could not use the school as a venue after all. (In the end, he let us use it.) A fourth challenge was that there was a snowstorm on the last day of the workshop and everything in town was closed, and I worried that the workshop would not be completed, but all the participants made it to the workshop through the storm to finish up their films. Although many of these logistical challenges are to be expected when doing CBR and when doing research in real life settings, doing CBR in a remote or northern context has additional challenges such as those associated with weather and travel. Overall, I found many of these challenges incredibly stressful at the time; however, I am very grateful that

everything worked out in the end, and the research participants were very engaged in the project and were not inconvenienced by the logistical challenges we faced.

5.6 Institutional barriers

In addition to these challenges, I faced a number of institutional barriers during the completion of this study and as Kovach (2015) writes, “to discuss liberating research methodologies without critical reflection on the university’s role in research and producing knowledge is impossible” (p.21). For instance, one challenge I faced involved the consent process. In my ethics application to the NL HREB, I requested that competent youth age 13 and older be able to consent for themselves, rather than needing parental or guardian consent. I requested this consent process for a number of reasons, including valuing the agency of competent participants and challenges related to parent/guardian relationships and the independence of youth in this community. In addition to these community-specific characteristics, having competent youth consent for themselves is a wise practice for involving youth and children in research (Brunger, 2009).

The research review committee for NunatuKavut approved my proposed consent process for competent youth. However, the NL HREB refused to allow competent youth to consent for themselves and I was required to have consent from parents or guardians. I opted to have youth assent to participate in the research as a way to involve them in the consent process. This raised issues for me regarding the role of Indigenous review boards and their relationship to institutional ethics boards. As the number of Indigenous review boards increases, protocols must be developed to help facilitate differences in decisions between boards.

5.6.1 Ownership, CBR, and arts-based research

I also faced multiple institutional barriers due to the creation of artistic products through research, namely, who owns these products. Those involved in CBR and those guided by the principles of OCAP® are challenging ideas of ownership in research. However, there still remains much to discuss regarding artistic products created through research, especially as arts-based research is increasingly taken up in academia. In the case of this workshop, an ownership plan for the films was made with the participants prior to their creation. It was important to me that the participants owned the films they created and had control over their use. In order to create the ownership plan for these films, and in order to release the grant funding to pay the film facilitators, my supervisor had to meet with the Office of Research Services, Research Grant and Contract Services, and the university's intellectual property lawyer to draft a contract and a copyright release form to accompany the informed consent form. Additionally, through this process I learned that if I was employed by my university, or funded through a supervisor's grant, the university would have a claim to any intellectual property arising from my research. For me this is problematic on a number of levels. For instance, many people are not aware of these ownership issues that can impact their relationships with, and the promises they make to, community partners and research participants. To me, this is critical when engaging in research with Indigenous Peoples, as guided by the principles of OCAP® and/or CBR, and arts-based research.

5.7 Tensions in the research

Reflecting on my doctoral journey, there were a number of other issues that arose. These issues are tensions I felt in the study design or other aspects of the research process. For instance, HIV/AIDS prevention is an extremely complicated issue. Being aware of the impact of colonialism on Indigenous health and wellbeing, I felt continual tensions in building my research on what may appear to be an individualistic intervention assessing knowledge and attitude change when research continues to suggest that reducing the incidence of HIV/AIDS within Indigenous communities requires major systemic changes. This tension was exacerbated by the fact that the knowledge and attitude change research question was asked by the community partner as it was useful information for applications for governmental funding. Knowledge and education programs are important and required for HIV prevention. But, HIV/AIDS infection rates are unlikely to decrease, and wellbeing is unlikely to improve, on a population level, without higher level structural change (Auerbach, Parkhurst, & Cáceres, 2011; Baral, Logie, Grosso, Wirtz, & Beyrer, 2013; Wilson et al., 2016). For me, situating the interest in knowledge and attitude improvement within a social ecological model of HIV prevention helped to alleviate this tension as this model recognizes that individual factors are only one level of factors that must be considered in order to address HIV prevention. Ultimately, HIV prevention requires a multi-level approach (Auerbach, Parkhurst, & Cáceres, 2011; Baral et al., 2013).

Similarly, during the course of this research, I have at times felt tension regarding the study design. Part of the research process was to develop an arts-based HIV/AIDS education workshop based on wise practices identified in the literature and grounded in

the local reality. Then, I was to do research on this workshop. The values shaping both the research and the workshop were similarly grounded in a community-based, arts-based, participatory, decolonizing, Indigenist, and critical approach. However, occasionally I would feel that these two distinct agendas would become tangled and conflated and I would gently try to tease them apart. I am not sure if this de-tangling was necessary, or if I had to consider them separately, but sometimes it was convenient and perhaps, as time progresses, my thoughts will evolve. In some ways I think part of the desire to see them separately was due to the northern/southern CBR tensions. Reflecting on this CBR process, I feel as though my relationship with the research partners was more closely aligned with the northern tradition of CBR in that it was focused on “collaborative utilization-focused research with practical goals of system improvement” (Wallerstein & Duran, 2008, p. 27). On the other hand, my relationship with the research participants was more closely aligned with the southern tradition, in that it was focused on “emancipatory research, which challenge[d] the historical colonizing practices of research and political domination of knowledge by the elites” (Wallerstein & Duran, 2008, p. 27).

Throughout my doctoral studies, I have also continued to think about two-eyed seeing and ontological difference. As stated in the introduction, I am very interested in two-eyed seeing. The environment created throughout the research process and at the workshop invited multiple ways of knowing. In order to more fully explore a two-eyed seeing approach I would have like to have had more participation from the research partners, had more input on the presentation of data, and incorporated a participatory data

analysis phase to the research process. However, the changes in staffing with the HIV/AIDS Labrador Project presented a challenge including with regard to organizing a participatory analysis phase. Likewise, the cost associated with hosting additional events was prohibitive.

5.8 Closing thoughts

As a graduate student, I was able to use my access to funding, knowledge, and skills to create a space for these experiences to take place. As I have given presentations in a variety of contexts about this project over the past few years, I have often realized the challenges of expressing the amazing energy and connection that was present at this workshop. I am grateful that the participants have given me permission to use their photos and films in my presentations as these films give another little window into their experiences, which is often missing when researchers present aggregate data, or even anonymous interview quotes. Their films have allowed these participants to be “present” at conferences, to share their experiences and creations, to show their faces and realities, and to speak. Their films are often very well received by audiences, and being able to “bring” participants to conferences in this way has been a great experience for me. However, I am also wary of this. I believe the research participants should continue to have control over the use of their images as well as creations. Additionally, ideally, it would be better to have community research partners and others involved in research attend and present more frequently at academic research conferences.

This doctoral journey has had a number of challenges, and many rewards. It has been a challenge to negotiate the university’s highly bureaucratic processes and to

conduct research far away from my home. Additionally, I have found that many of the resources and literature in this field have only emerged over the last few years. Although there were times where I wished for more guidance from the literature, I think this is also exciting as it suggests that this research is extremely timely!

In sum, the purpose of this study was to look at the use of participatory filmmaking as a strategy for HIV/AIDS education with Indigenous youth. Through the development of this innovative, participatory, culturally grounded, decolonizing, and empowering arts-based workshop, we were not only able to engage a group of amazing youth, but also engage with a group of Elders in discussion about HIV/AIDS, sexual health, and health in general. This participatory arts-based strategy demonstrated the flexibility and appeal required to engage intergenerational participants in fruitful collaborations, contribute to the development of new knowledge and skills for youth and Elders alike, and it was perceived as a decolonizing approach where participants felt ownership over their experiences. I am incredibly grateful to the Elders and youth who participated in this research and shared their experiences and creativity. I developed relationships with many of them through this project and continue to visit with them when I am in Labrador.

This study is one of the first to explore the effectiveness and participants' experiences of an arts-based HIV/AIDS prevention strategy for Indigenous youth. It provides a unique contribution to the literature on HIV prevention for Indigenous youth and arts-based research offering an assessment of the benefit of an arts-based strategy as a tool for health promotion within an Indigenous context. In addition to the academic

significance of this research, it is my hope that the practical implications, the findings and recommendations from this study, contribute to the development of health promotion programming and policy in order to address HIV/AIDS, sexual health, and wellbeing in culturally-safe, decolonizing, participatory, effective, and fun ways for Indigenous communities in Canada and beyond.

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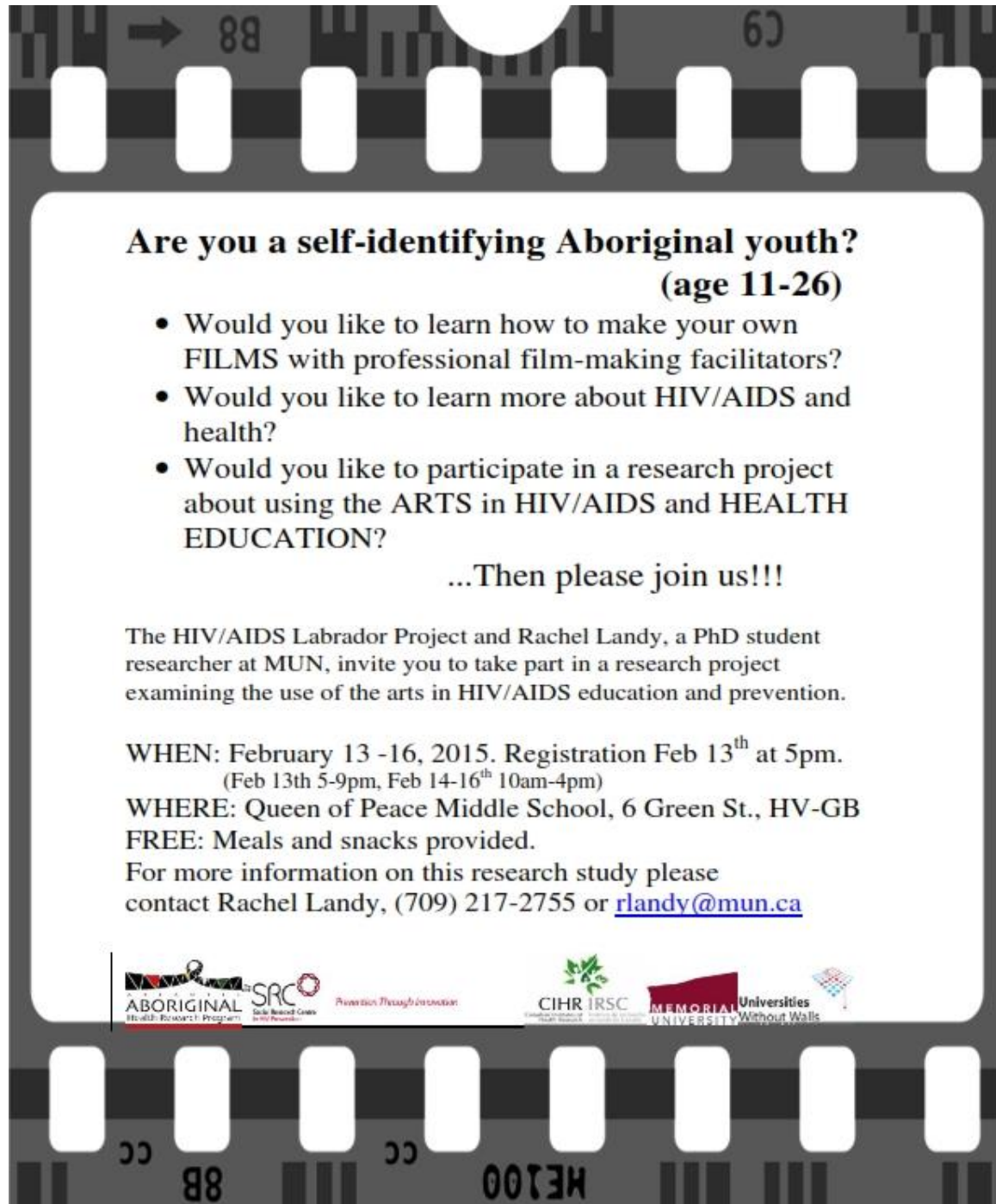
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Appendix A: Timeline

March 2012	Initial emails and phone calls with the coordinator of the HIV/AIDS Labrador Project
April 2012	Introductory letter to LFC about who I am, what my research interests are, partnership details, funding opportunities circulated to HIV/AIDS Project Advisory Committee
May 2012	First draft of research proposal to HIV/AIDS Project and LFC for review Application to AAHRP doctoral funding, Harris Centre funding
September 2012	Attend Ethic workshop Meet with HIV/AIDS project coordinator in HV-GB Meet with LFC executive Director Meeting with Lab-Grenfell Health, Innu Nation Apply for funding (CIHR)
January 2013	Apply for ethics approval-in-principle
February 2013	Apply to the Harris Centre (again)
May 2013	Apply to AAHRP project funding
July 2013	Apply for ethics approval from HREB and for approval from NunatuKavut
September 2013	Advisory Committee Meeting in HV-GB Meetings with Stakeholders Marathon
November 2013	Meetings in HV-GB Participate in the Labrador Creative Arts Festival
December 2013	Apply to Social Research Centre in HIV Prevention
February 2014	Successful SRC
March 2014	Comprehensive Exams
April 2014	Apply for UWW.2
August 2014	HIV/AIDS Labrador Project Coordinator resigned
November/December 2014	Meeting with new coordinator, Plans for youth survey on types of arts, Meet with youth coordinators around HV-GB LCAF
December 2014	New coordinator resigns
February 2015	Stakeholder meetings Plans for workshop/logistics Workshop implementation CBR Capacity building workshop (open to public, funded through my UWW fellowship, run in partnership with CAAN)
February/March 2015	Interviews Finalization of films

April 2015	Film Debut – Community Event
	Stakeholder meetings
	HIV/AIDS Labrador Project Coordinator resigns
December 2016	Assist LFC in development of PHAC funding proposal
April/May 2017	Present some findings at Rural Remote Research Conference
	Present to staff of LFC
	Meet with HIV/AIDS program coordinator and youth coordinator at LFC

Appendix B: Recruitment Poster



Are you a self-identifying Aboriginal youth?
(age 11-26)

- Would you like to learn how to make your own FILMS with professional film-making facilitators?
- Would you like to learn more about HIV/AIDS and health?
- Would you like to participate in a research project about using the ARTS in HIV/AIDS and HEALTH EDUCATION?

...Then please join us!!!


The HIV/AIDS Labrador Project and Rachel Landy, a PhD student researcher at MUN, invite you to take part in a research project examining the use of the arts in HIV/AIDS education and prevention.

WHEN: February 13 -16, 2015. Registration Feb 13th at 5pm.
(Feb 13th 5-9pm, Feb 14-16th 10am-4pm)

WHERE: Queen of Peace Middle School, 6 Green St., HV-GB

FREE: Meals and snacks provided.

For more information on this research study please contact Rachel Landy, (709) 217-2755 or rlandy@mun.ca



Appendix C Consent Forms



Faculty of Medicine
Division of Community Health and Humanities
The Health Sciences Centre
St. John's, NL, Canada A1B 3V6
Tel: 709-757-4155

Consent to Take Part in Research

Research Title: Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project

Researcher: Rachel Landy, Faculty of Medicine, Memorial University of Newfoundland
Supervisors: Dr. Natalie Beausoleil & Dr. Mario Blaser

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide if you want to be part of the study or not. You can decide not to take part in the study. If you decide to take part, you are free to stop participating at any time. If you decide to stop, you will keep the gift you received for participation

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This is a consent form. It explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. Please ask questions about anything that is not clear.

The researcher (Rachel Landy) will:

- discuss the study with you
- answer your questions
- keep confidential, within the parameters of the law, any information which could identify you personally
- be available during the study to deal with problems and answer questions

Introduction/Background:

I am a PhD student researcher from Memorial University. I want to find out whether creating art can be a way to teach about HIV. I want to know if the arts can be used for education programs for Inuit, Métis and First Nations youth. I want to know more about the types of arts that youth choose and what youth think about using the arts. I also want to know how youth might use art to talk about health.

The rates of HIV are high among Aboriginal people in Canada. The Labrador Friendship Centre offers HIV education. Together, we are exploring the use of the arts as one way to teach youth. We are going to try this out by holding an HIV education arts workshop for Aboriginal youth ages 11-26.

What you will do in this study:

Workshop: If you choose to be in this study, you will attend a 3 ½ day workshop (Friday 5-8pm, Saturday 9-5 and Sunday 9-5). Lunch and snacks will be provided. During this workshop you will hear presentations about health, HIV, and AIDS. You will learn about making films from video artists and facilitators. You will get to make your own artistic creations and you will make a film in a group with other participants. At the end of the workshop, if you like, you will have a chance to show your artwork to your friends and family.

Interview: Within two weeks of the end of this workshop, you will be invited for an interview. During the interview you will be asked about your experiences at the workshop. There are no right or wrong answers. You do not have to answer any question you do not want to answer. This interview will be with Rachel Landy. It will take place somewhere we agree upon together. This interview will take ½ - 1 hour.

Possible benefits and risks

Possible Benefits

It is not known whether this study will benefit you. Some people may find it helpful to talk about their health and to learn about HIV and AIDS. Some people may find it fun to create art and work with their peers.

Possible risks

There may be some risk from participating in this study:

- Talking about health and issues around HIV and AIDS can be emotional, especially if your experiences have been difficult.
- If you become upset at any time you may stop, or choose to not answer a question. If you would like to talk to someone about your feelings or issues raised by this study, there are health professionals available for you to meet with:
 - * Megan Hudson
Public Health Nurse, Lab Grenfell
and Addictions
 - * Amanda Pardy
Intake Worker, Mental Health

megan.hudson@lghealth.ca
709-897-2243

Amanda.pardy@lghealth.ca
709-897-2355

Confidentiality and Storage of Information

Recording our interview

- I would like to audio record our interview so that I can review what was talked about. You can request that any statement be kept “off the record” and/or have the recorder turned off.
- All interview recordings will be typed up and you will be asked if you would like to read the typed version of your interview. If you do, you may add, change or delete things as you want.
- Video and photography may be used during the workshop. You do not have to be in the video or photographs if you would rather not be.

Privacy

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. Other people taking part in the workshop may know your name and hear your comments. People may identify you by the art work you made during the workshop. The artists will sign an oath to say they will treat any information you may share as confidential. Depending on what you and your co-creators decide to do with the films you made (for instance releasing the film on the Internet), you may be identifiable. Once the films have been made and you have a copy of the film, the research team will not be able to control who has access to it. That control will be in the hands of the participants who made the film.

All participants will be reminded to:

- respect the privacy of each member of the group
- treat all information shared with the group as confidential

When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

I will do everything that I can to protect your privacy. But if you tell me that you have the intention to hurt yourself or someone else, or you tell me that you are being abused by someone, I am required to report that.

Anything that is written about this study will not identify you without your permission. You may choose to be referred to by a made-up name of your choice. Images of the art made by you will only be used with your permission.

Storing Information from this study:

All consent forms, recordings and transcripts will be stored securely in my office in Happy Valley-Goose Bay. Anything electronic will be password-protected on my computer. Information collected from this study will be kept for 5 years.

You will keep the artistic works you make during this workshop. As a group we will discuss options for displaying these creations but your work will remain your own. You will decide what you would like to do with it. The films made in a group will be owned by the group.

Access to records

The members of the research team will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only while supervised by a member of the research team.

You may ask Rachel Landy to see any information that has been collected about you.

Reporting research results

The data I collect will be used for:

- My university doctoral thesis
- Submission to academic journals
- Community reports
- Reports to government and other groups that may be interested in the results from this study
- Presentations

Questions:

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact:

Rachel Landy
supervisor)

Graduate Student (PhD candidate)
Humanities

Division of Community Health and Humanities
Faculty of Medicine
Memorial University
(709) 757-4155
rlandy@mun.ca

Dr. Natalie Beausoleil (thesis

Division of Community Health and

Faculty of Medicine
Memorial University
St. John's, NL, A1B 3V6
(709) 777-8483
natalie.beausoleil@med.mun.ca

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Research Ethics Authority

709-777-6974 or by email at info@hrea.ca

The proposal for this research has been reviewed by the Health Research Ethics Board (HREB) and found in compliance with the Tri-Council Policy Statement. If you have ethical concerns about the research you may contact the HREB Ethics Office at info@hrea.ca or telephone (709) 777-6974.

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

After signing this consent you will be given a copy.

To be signed by the minor participant

Study title: Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project

Name of principal investigator: Rachel Landy

Assent of minor participant:

I understand the purpose of this research.

I understand that it is my decision to take part in this study. I can stop taking part if I chose.

I understand that taking part in this research may not help me.

I understand that there may be risks to participating in this study.

I agree that I will take part in this study.

Signature of minor participant

Day/Month/Year

Name printed

Age

Signature Page for Parent/Guardian

Study title: Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project

Name of principal investigator: Rachel Landy

To be filled out and signed by the parent/guardian:

Please check as appropriate:

- | | | |
|--|---------|--------|
| I have read the consent. | Yes { } | No { } |
| I have had the opportunity to ask questions/to discuss this study. | Yes { } | No { } |
| I have received satisfactory answers to all of my questions. | Yes { } | No { } |
| I have received enough information about the study. | Yes { } | No { } |
| I have spoken to Rachel Landy and he/she has answered my questions. | Yes { } | No { } |
| I understand that I am free to withdraw my child/ward from the study. | Yes { } | No { } |
| • at any time | | |
| • without having to give a reason | | |
| • without affecting future care | | |
| I agree that the research team may audio/video tape interviews. | Yes { } | No { } |
| I agree that my child may be videotaped or photographed during the workshop. | Yes { } | No { } |
| I understand that it is my choice for child/ward to be in the study and that he/she may not benefit from participation. | Yes { } | No { } |
| I understand how my child/ward's privacy is protected and records are kept confidential. | Yes { } | No { } |
| I understand that my child will own or co-own the artist works they create. | Yes { } | No { } |
| I agree that any circulation of the artistic works created during the workshop will only be in the case where all co-owners consent. | Yes { } | No { } |

I consent for my child/ward _____(Print Name)_____to take part in this study.

Signature of parent/guardian	Name printed	Day/Month/Year
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To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the parent/guardian fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen for the child/ward to be in the study.

Signature of investigator	Name Printed	Day/Month/Year
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Copyright Release Form - Participant

This is a copyright release form for the research project titled: *“Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project.”*

You, the participant, own or co-own the creative pieces that you make during this workshop.

- I am asking that you give me permission to talk about and show parts of your creation in my thesis, in the presentations I give about this research and publications resulting from this research.

This was created under an agreement to fulfill the purposes of participating in a research project.

I, _____, give permission to Rachel Landy (Principal Investigator) to have use of the film and creative materials that I created in this workshop which Rachel Landy intends to use for the research project *“Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project”* including in her thesis, presentations and papers arising from this research.

It should be noted that once Rachel Landy’s PhD thesis or any related papers or presentations are published, I understand that I will not have the option of changing my mind and removing my materials.

If you agree, please sign your name and provide a signature below.

Print Name

Date

Signature

Copyright Release Form - Guardian

This is a copyright release form for the research project titled: *“Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project.”*

This was created under an agreement to fulfill the purposes of participating in a research project.

Your child, owns or co-owns the creative pieces that he/she makes during this workshop.

- I am asking that you give me permission to talk about and show parts of your child’s creation in my thesis, in the presentations I give about this research and publications resulting from this research.

I, _____, give permission to Rachel Landy (Principal

Investigator) to have use of the film and creative materials that my child,

_____, created in this workshop which Rachel Landy intends to use for the research project *“Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: A community-based participatory action research project”* including in her thesis, presentations and papers arising from this research.

It should be noted that once Rachel Landy’s PhD thesis or any related papers or presentations are published, I understand that I will not have the option of changing my mind and removing my child’s materials.

Print Name

Date

Signature

Appendix D: Workshop Schedule

Filmmaking and HIV/AIDS/health education workshop schedule

Friday, February 13, 2015 5-9pm

- 5pm Introduction -who we are, what we are doing, why are we making film, who do we want to see the film, everyone will get a DVD, discuss community film screening and putting films on YouTube
- Opening circle, name a movie you like
- Movement game
- Opening by Elders (lighting of Kudlik-if possible; words of encouragement and greeting)
- Ice breaker
- Pre-test
- 6:00 -6:30 pm Dinner
- 6:30 pm Group A: HIV Workshop; Group B: Community agreements
- 8:20pm Closing circle

Saturday, February 14, 2015 10am -4pm

Morning:

- Opening Circle & Icebreakers
- Group A: Community Agreements; Group B: HIV Workshop
- 12:30 Lunch
- 1pm Movement games
- Film Planning
- 3pm Sharing Circle with Elders
- 3:40 Closing Circle for both groups

Sunday 10am -4pm

- Opening Circle & Icebreakers
- Group A & B: Shooting a film
- 12:30 Lunch
- 1pm Movement games
- Shooting films cont'd
- 3pm Group B: Sharing Circle with Elders
- 3:40 Closing Circle for both groups

Monday, February 16th, 2015 10am -4pm

- Morning Gathering
- Icebreaker games
- Editing films
- 12:30 lunch
- 1pm movement games
- Editing films cont'd

- 2pm Showing the films - works in progress
- 2:30pm Sharing circle with everyone
- Posttest & Wrap up
- Closing by Elder

Appendix E: HIV/AIDS Knowledge and Attitude Questionnaire

HIV/AIDS Knowledge			
Coughing and sneezing DO NOT spread HIV.	True	False	Don't know
A person can get HIV by sharing a glass of water with someone who has HIV.	True	False	Don't know
Pulling out the penis before a man climaxes/cums keeps a woman from getting HIV during sex.	True	False	Don't know
A woman can get HIV if she has anal sex with a man.	True	False	Don't know
Showering, or washing one's genitals/private parts, after sex keeps a person from getting HIV.	True	False	Don't know
All pregnant women infected with HIV will have babies born with AIDS	True	False	Don't know
People who have been infected with HIV quickly show serious signs of being infected.	True	False	Don't know
There is a vaccine that can stop adults from getting HIV.	True	False	Don't know
People are likely to get HIV by deep kissing, putting their tongue in their partner's mouth, if their partner has HIV.	True	False	Don't know
A woman cannot get HIV if she has sex during her period.	True	False	Don't know
There is a female condom that can help decrease a woman's chance of getting HIV.	True	False	Don't know
A natural skin condom works better against HIV than does a latex condom.	True	False	Don't know
A person will NOT get HIV if she or he is taking antibiotics.	True	False	Don't know
Having sex with more than one partner can increase a person's chance of being infected with HIV.	True	False	Don't know
Taking a test for HIV one week after having sex will tell a person if she or he has HIV.	True	False	Don't know
A person can get HIV by sitting in a hot tub or a swimming pool with a person who has HIV.	True	False	Don't know
A person can get HIV from oral sex.	True	False	Don't know
Using Vaseline or baby oil with condoms lowers the chance of getting HIV.	True	False	Don't know

Adapted from Carey & Schroder, 2002.

Attitudes			
I wouldn't mind being in the same classroom with someone who has HIV.	True	False	Don't know
A person who has HIV/AIDS shouldn't be allowed to eat lunch in the school cafeteria.	True	False	Don't know
I wouldn't mind swimming in the same pool as someone who has HIV/AIDS.	True	False	Don't know
I would feel comfortable hugging a close friend who has HIV/AIDS.	True	False	Don't know
I wouldn't mind playing sports with someone who has HIV/AIDS.	True	False	Don't know
A person who has HIV/AIDS should stay away from public places.	True	False	Don't know
I would avoid a classmate who I heard has HIV/AIDS.	True	False	Don't know
People who have HIV/AIDS should be allowed to work in restaurants and cafeterias.	True	False	Don't know
If I thought my friend had HIV/AIDS, I would be afraid to give that friend a kiss.	True	False	Don't know
I would avoid a classmate whose family member has HIV/AIDS.	True	False	Don't know

Adapted from Popham et al., 1992.

Appendix F: Interview Guide - Youth Participants

- 1) What made you decide to participate in this workshop? Why did you choose to participate in this workshop?
- 2) What were you expecting when you decided to participate in this workshop? Did anything surprise you?
- 3) Tell me about how you made this “art”?
 - a. Did you work in a group? Did you work alone?
- 4) How does your art relate to HIV/AIDS prevention or health in general?
 - a. What kind of things did you talk about while you were making?
- 5) Did you enjoy making art? What did you like about it?
- 6) Are you an artistic or creative person?
- 7) What kind of art activities have you done in the past?
- 8) How did you like sharing your artwork with the peers and parents?
- 9) Do you have anything else you would like to tell the researchers?

Appendix G: Knowledge Dissemination Activities

- Landy, R. "Closing the Gap: Involving Indigenous Elders and youth in HIV/AIDS prevention using participatory filmmaking." The Ninth International Congress on Arctic Social Science, Umea, Sweden, June 8 – 12, 2017.
- Landy, R. "Participatory filmmaking as a strategy for health education with Indigenous youth and Elders in Labrador." Labrador Research Forum. Happy Valley-Goose Bay, Labrador, April 30–May 3, 2017.
- Landy, R. "Experiences of youth participating in an intergenerational participatory filmmaking and HIV/AIDS education workshop." Canadian Association for HIV Research Conference, Montreal, QC, April 6–8, 2017.
- Landy, R. "Closing the Gap: Involving Elders in HIV/AIDS education and prevention with Indigenous youth." National Gathering of Graduate Students. Ottawa, ON, June 12–14, 2016.
- Landy, R. "'Condom in Grandma's Bag:' Experiences of Elders participating in an arts-based HIV/AIDS education workshop for Aboriginal youth" Canadian Association for HIV Research Conference, Winnipeg, MB, May 13, 2016.
- Landy, R. "Participatory filmmaking and HIV/AIDS Education with Aboriginal Youth" Research Exchange Group on the Arts & Health, Newfoundland and Labrador Centre for Applied Health Research, St. John's, NL, April 5, 2016.
- Landy, R. "Condom in Grandma's Bag:" Experiences of Elders participating in an arts-based HIV/AIDS education workshop for Aboriginal youth. Aboriginal Speaker Series, Memorial University of Newfoundland, St. John's NL, February 16, 2016.

Landy, R. "Lessons learned: a graduate student's CBR experience using participatory filmmaking with Indigenous youth and Elders in an HIV/AIDS education and prevention program." ACUNS 2015 Student Conference, Calgary, Alberta, November 5–8, 2015

Landy, R. "Condom in Grandma's Bag": Elders and youth want to talk about sex. Wise Practices V, Vancouver, Canada, July 17–18, 2015.

Landy, R. & Amirault, M. Films in Research: Fun with data collection. Wise Practices V, Vancouver, Canada, July 17–18, 2015.

Landy, R. Participatory film-making with Aboriginal youth and Elders: a doctoral journey through an arts and community- based research project. National Gathering of Graduate Students, Vancouver, British Columbia, July 12–14, 2015.

Landy, R., Flicker, S., & Switzer, S. (2015). Zoom In 2 Zoom Out: Using Photography In Your Research. Universities Without Walls Summer Learning Institute, Toronto. June 9–12, 2015.

Landy, R. Adventures in Community-Based Research. Universities Without Walls Online Colloquium Webinar Series, May 27, 2015.

Panalist. Journeys after STIHR Graduation. 4th Annual Cross-STIHR Research Day, University of Toronto, Toronto, Ontario, April 25, 2014.

Landy, R. Facilitated/presented on panel "HIV in Northern Canada." Ontario HIV Treatment Network Conference, Toronto, Ontario, November 17–19, 2013.

- Landy, R. “Arts-based HIV/AIDS Education for Aboriginal Youth in Labrador: a community-based participatory action research project proposal” National Gathering of Graduate Students, Vancouver. June 2013.
- Landy, R. “Music-based HIV education with Aboriginal Youth” *CPHA Annual Conference*, Edmonton, Alberta. June 2012.

PUBLIC PRESENTATIONS

- Landy, R. Film Screening. Labrador Creative Arts Festival. Happy Valley-Goose Bay, Labrador, November 21, 2015.
- Landy, R. Film Festival: Debuting films made by Elders and youth in Happy Valley-Goose Bay, Labrador, April 23, 2015.
- Host, Aboriginal Health and Community-Based Research Capacity Building Meeting, Happy Valley-Goose Bay. February 24–25, 2015.