

Positive Aging: Indigenous Peoples Aging with HIV/AIDS

Positive Aging: Indigenous Peoples Aging with HIV/AIDS

By CHANEESA RYAN, B.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the  
Requirements for the Degree Master of Arts

McMaster University MASTER OF ARTS (2016) Hamilton, Ontario (Health, Aging, and Society)

TITLE: Positive Aging:

Indigenous Peoples Aging with HIV/AIDS

AUTHOR: Chaneesa Ryan, B.A.

SUPERVISOR: Dr. Chelsea Gabel

NUMBER OF PAGES: vi, 135

## Abstract

As a result of advances in treatment over the past 30 years, the number of older people living with HIV is growing. This is of particular concern for Indigenous populations in Canada given continuing over representation in HIV diagnoses. While there has been an increase in research on aging with HIV within the general population, little is known about the experiences of older positive Indigenous peoples.

Research was conducted in partnership with the Canadian Aboriginal AIDS Network (CAAN) at CAAN's Wise Practices V conference. Participants were conference delegates, representing a sample of First Nations, Inuit and Métis people living with HIV and/or service providers from across Canada. Participants ranged in age from 32 to 63 and had been positive for 5 to 29 years. Data was collected through four sharing circles (two with women, one with men and one with service providers) and four interviews (n=34).

An open analytic approach was used to explore the content of the transcripts and codes were collaboratively developed by the research team through an inductive and iterative process. From our analysis we were able to develop an Indigenous model of successful aging (SA). This proposed Indigenous model of SA represents a holistic and subjective model that is far more achievable than traditional models of SA. Within this model five dimensions of health and wellness emerged as facilitators of SA: physical, emotional, spiritual, mental and social health. Additionally, resilience, age and culture were found to be protective factors to SA.

The goal of this project was to identify facilitators and individual strategies which enable SA within this population, in order to develop culturally mediated responses. Ideally, this knowledge can be used to help structure community and primary health services to promote SA with HIV in ways which are congruent with Indigenous culturally-defined notions of health.

## Acknowledgments

Over the past two years I have received unwavering support and encouragement from a great number of individuals. First and foremost, I would like to thank my thesis supervisor Dr. Chelsea Gabel for her continual positive direction and reassurance throughout this whole process. Your ability to manage all of the great work that you do while still finding time to always make yourself available to help is impressive to say the least. Thank you so much for sharing your passion, knowledge and positive spirit with me. I would like to express my sincere gratitude to Randy Jackson, without whom this project would not be possible. Thank you for inviting me to work on this project and by extension, providing me with the opportunity to be a part of a truly inspiring community of people. Your immense knowledge, passion, patience and easy going nature was motivational and inspirational. Combined, the support and enthusiasm you have both provided me with has given me such confidence.

I must offer a very sincere thank you to Renee Masching and Dr. Alexandra King for welcoming me to be a part of the research team. Without your insights on this topic and feedback on my work this project would not be the same. To members of the Canadian Aboriginal Aids Network, thank you, miigwetch for welcoming me into your community and sharing your stories with me. I learned so much from all of you and I am not referring to aging with HIV. Your strength, wisdom and zeal for life is truly inspiring. Thank you to the Elders who so willingly joined this project despite having no prior knowledge about it. Your very presence in our sharing circles was supportive and uplifting. A special thank you to Elder Cliff Thomas or “the bad Elder”, for his continued support within and outside of the sharing circles throughout the course of the week of Wise Practices V events. Your kindness, wisdom, humor and friendship provided me with more support than you probably realize.

I am honored and humbled to have had the opportunity to work on such a meaningful project with a group of truly inspiring people. Lastly, I need to acknowledge the generous contributions from the Canadian Institute of Health Research Institute of Aboriginal People’s Health, for without this financial support this project would not be possible.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION.....7

CHAPTER TWO: THEORETICAL PERSPECTIVE.....22

CHAPTER THREE: LITERATURE REVIEW.....30

CHAPTER FOUR: METHODS.....55

CHAPTER FIVE: FINDINGS.....78

CHAPTER SIX: CONCLUSIONS.....106

REFERENCES.....113

APPENDICES.....

    Appendix A .....127

    Appendix B.....131

    Appendix C.....134

    Appendix D.....135

## **Chapter One: Introduction**

### **Indigenous Peoples in Canada**

As of 2011, there are approximately 1,400,685 in Canada who identify as Indigenous (First Nations, Inuit or Métis), representing 4.3% of the total Canadian population (Statistics Canada, 2015). Indigenous peoples across Canada share a similar story, one of violence and oppression since first contact with the Europeans. Over five hundred years of colonization has resulted in myriad social, political and economic inequalities suffered by Indigenous peoples which all work together to negatively impact their health (King, Smith & Gacey, 2009). While understanding the causes of these differences in health status, such as the disproportionate rate of HIV infections, is critical, it goes beyond the scope of this thesis. However, a holistic discussion of Indigenous health cannot take place without making reference to colonialism. In particular, the residential school system was arguably one of the most aggressive colonial policies in Canada, which forcibly removed Indigenous children from their homes in order to ‘civilize’ them (Wilson, Rosenberg & Abonyi, 2011). In addition to the now well known cases of physical, mental, cultural and sexual abuse experienced by Indigenous students, the residential school system has also resulted in a significant loss of cultural knowledge (Wilson et al., 2011). Residential school survivors largely make up the current demographic of older Indigenous peoples with and without HIV. The legacy of abuse perpetuated by colonizing forces has undermined and continues to systemically undermine Indigenous peoples, resulting in major health inequalities. It can be said that the current state of Indigenous people’s health in Canada is a direct consequence of this legacy of abuse (Truth and Reconciliation Commission of Canada, 2015). Despite attempts to erode Indigenous cultures and thus, assimilate Indigenous peoples

into mainstream Canadian culture, Indigenous cultures, communities and individuals are healing themselves (which can be demonstrated through cultural revitalization movements happening in Indigenous populations across the country).

While there is a vast diversity amongst Indigenous languages, cultures, values, traditions and ceremonies, Indigenous peoples of Canada and North America share a similar world view which shapes their ways of life (King et al., 2009). The fact that this research focuses on all Indigenous peoples with HIV as a whole and does not focus on one of Canada's three Indigenous groups: First Nations, Inuit or Métis, or further, a specific nation or even community, is by no means a way to try to generalize and homogenize this population. Rather, this research is about honouring the heterogeneity of Indigenous peoples in this country while exploring common ideas around successful aging and facilitators which help to enable Indigenous peoples to age successfully from a culturally resonate approach.

### **Indigenous Peoples and HIV/AIDS**

Indigenous peoples in Canada experience disproportionate rates of chronic and infectious diseases, higher rates of substance abuse, suicide and addictions and an overall lower life expectancy than their non-Indigenous Canadian counterparts (Adelson, 2005). Despite only making up 4.3% of the Canadian population, in 2011, Indigenous peoples made up 8.9% of the HIV positive population in Canada and 12.2% of all new diagnoses that year (PHAC, 2014). In Canada, the Indigenous population is comprised of three groups: First Nations, Inuit and Métis. Indigenous Canadians are 3.5 times more likely to acquire HIV than non-Indigenous Canadians



(PHAC, 2014). The Public Health Agency of Canada (PHAC) (2014) recognizes Indigenous peoples as a unique segment of the nations concentrated HIV epidemic due to their younger age at time of infection and to the significantly higher number of infections attributed to the exposure category of injection drug use. For these reasons, PHAC (2014) highlights the need for culturally relevant interventions for prevention, treatment, care and support for this population.

HIV is shifting from a primarily infectious, deadly disease, to a more chronic, manageable condition (Cahill & Valadez, 2013). This means that HIV is no longer a death sentence, and people are living longer, healthier lives (Indigenous and non-Indigenous people alike). The Canadian Aboriginal AIDS Network (CAAN) members have expressed concern about a lack of culturally mediated knowledge surrounding aging with HIV. This research project was formulated in response to these concerns, seeking to better understand the lived experiences of older Indigenous peoples living with HIV/AIDS.

### **HIV/AIDS and Aging**

Despite the fact that age 65 commonly signifies senior status, for the purpose of this research, older adults describes those over the age of 50. Many organizations and health care professionals offer services for seniors to Indigenous people younger than 65 due to their shorter life expectancy and their earlier onset of chronic conditions in comparison to other Canadians (Health Council of Canada, 2013). Furthermore, the age 50 is commonly used in the HIV and aging literature to denote old age (Brennan, Emler, Brennenstuhl & Rueda, 2013; Poindexter & Keigher, 2004). This change in the chronological categorization of old age is partially attributed

to the beginning of the epidemic when HIV was viewed as a death sentence. Additionally, it is commonly believed that HIV causes premature aging (Deeks & Phillips, 2009). Lastly, statistics from both Canada and the United States demonstrate that the proportion of individuals living with HIV over the age of 50 is steadily increasing (Brennan et al., 2013).

While the HIV positive Indigenous population is younger than their non-Indigenous counterparts, 69.3% of Indigenous peoples with HIV are 30-49 years old (PHAC, 2014). This suggests that over the next two decades, the number of older Indigenous peoples living with HIV/AIDS is going to rapidly increase. This is significant because for the first time in the history of the epidemic more than 50% of people living with HIV/AIDS in the United States of America are over the age of 50 (Brennan, Emler & Eady; 2011; Ellman et al., 2014; Hansen et al., 2013; Jang, Anderson & Mentis, 2011). While the prevalence of HIV within this cohort of “older adults” is not quite as high in Canada and the rest of the developed and undeveloped world, there is evidence that the aging of the HIV/AIDS epidemic is a global phenomenon. This phenomenon has been characterized by some, as the “greying of the HIV/AIDS epidemic” (Beaulaurier, Craig & De La Rosa, 2009; Beuthin, Bruce & Shields, 2015; Emler & Shippy, 2008; Grov et al., 2010; Haile, Padilla & Parker, 2011; Mueller, 1997; Nevedal & Sankar, 2015; Orel, Stelle & Watson, 2008; Stormholm et al., 2013). The HIV/AIDS epidemic in Canada is not exempt from these findings. In fact, in July of 2010, PHAC published an *HIV/AIDS Epidemic Update* which included a chapter on older Canadians (chapter 6). The report clearly illustrated the increasing proportion of positive HIV tests among older adults. The report stated, “the number of annual positive HIV test reports has increased among those 50 years old and over by 76.5% since 1999” (PHAC, 2010, p.3). Additionally, PHAC (2010) has reported a 35.8% increase in total AIDS

cases among older Canadians in the last 10 years. Furthermore, the report identified a number of significant trends in HIV/AIDS prevention, diagnosis and treatment/outcomes specific to older Canadians. Chapter Six of the *HIV/AIDS Epidemic Update* highlighted the following trends: 1) research has shown that older Canadians are less informed about HIV/AIDS transmission than their younger counter parts, 2) physicians are less likely to discuss sexual health with older patients, 3) the 50 plus age group has the highest percentage of any age group reporting unprotected risk, putting them at higher risk of HIV infection, and 4) in addition to the limited knowledge of HIV transmission older Canadians are less likely to be tested for HIV (PHAC, 2010). Despite all of these findings a focus on HIV/AIDS among the aging population is absent from the *Federal initiative to Address HIV/AIDS in Canada*. Unfortunately, without such recognition these trends show no signs of decline in the near future.

The “greying of the epidemic” can be attributed to the advent of antiretroviral therapy which means that people are living longer lives and are now aging into their 50’s, and less so to the growing incidences of HIV diagnoses in individuals over the age of 50 (Balderson et al., 2013; Brennan, 2008; Cahill & Caladez, 2013; Ellman et al., 2014; Foster & Gaskins, 2009; Heckman et al., 2002; Owen & Catalan, 2012; Psaros et al., 2015; Roger, Mignone & Kirkland, 2013; Siconolfi et al., 2013; Siemon et al., 2013; Solomon et al., 2014; Stormholm et al., 2013; Vance, Struzick & Childs, 2010; Wallach & Brotman, 2013). Ellman et al. (2014) state that, “as of 2011 persons aged 50 and older comprised 17% of new HIV diagnoses and 25% of all AIDS diagnoses in the United States” (p.530). This increase in new diagnoses in individuals over the age of 50 has been attributed to a number of reasons including a lack of sexual health knowledge and education targeted at the older population, lower levels of testing due to this lack of

knowledge and ageist stereotypes held by health care workers, as well as a number of age related biological susceptibilities which will be explained in more detail in the literature review in Chapter Three. What is even more alarming about this finding is the fact that a large percentage of those newly diagnosed with HIV aged 50 and over are at an advanced stage of the disease upon diagnosis (Balderson et al., 2013; Ellman et al., 2014). Furthermore, the Centers for Disease Control and Prevention (CDC) have disclosed statistics that show adults aged 50 and over are more likely to progress to AIDS within a one-year period of their HIV diagnosis than their younger counterparts. Ellman et al. (2014) have also identified that there are greater racial and ethnic disparities in HIV diagnoses amongst the 50 plus population.

People living with HIV/AIDS (PLHA's) in the developed world, who begin highly active antiretroviral treatment (HAART) early on, can now expect to live well into their 70's (Cahill & Valadez, 2013). Thus, HIV has shifted from a primarily infectious, deadly disease, to a more chronic, manageable condition (Cahill & Valadez, 2013). This means that HIV is no longer a death sentence, people are living longer, healthier lives. Although this positive shift has taken place the greying of the epidemic has been recognized as an up and coming global health concern (Beuthin, Bruce, & Sheild, 2015; Ornel, Stelle & Watson, 2008). Beuthin et al. (2015) highlight the fact that, "the day-to-day experiences, realities, and challenges of affected individuals remain largely invisible" (p.1). Ultimately, as individuals living with HIV age, management of the disease becomes more complex.

Older adults with HIV experience a myriad of health challenges but due to the fact that aging with HIV is a relatively new phenomenon, many of the associated health challenges are

not very well understood. Balderson and his colleagues (2013) found that, “coupled with the aging process, the extended exposure of these older adults to both HIV and antiretroviral drugs appears to increase their risk of illness and death from HIV associated non-AIDS conditions such as cardiovascular, bone, kidney, liver, and lung disease, as well as many cancers not associated directly with HIV infection” (p.451). The link between, aging, HIV and the high prevalence of comorbidities is one of the most commonly cited complications discussed in the literature in relation to older adults living with HIV. In a study conducted by Brennan-Ing et al. (2013) their findings confirm the significant prevalence of comorbidities within the aging HIV population, adding that these comorbidities have a much earlier onset. These co-occurring health conditions make aging with HIV more difficult to manage and treat (Balderson et al., 2013; Cahill & Caladez, 2013; Cresswell & Fisher, 2013; Deeks, & Phillips, 2009; Solomon et al., 2014). HIV has also been associated with the idea of accelerated aging. Cahill and Caladez (2013) point out evidence which suggests that this is the case, stating that HIV can reduce a person infected with the disease T-cell counts similar to that of a person who is 20 to 30 years their senior. However, Cresswell and Fisher (2013) state that while age does influence the course of the disease, and speeds up the progression to AIDS and mortality, the correlation between HIV and accelerated aging remains unclear.

In addition to the physical health challenges related to aging with HIV, there are a variety of social and emotional challenges, such as; depression, loneliness, stigma and social isolation. These psychosocial issues are commonly experienced by many individuals with HIV, however, for older adults, these psychological stressors may be intensified due to interactions with the aging process (Groves et al., 2010). In addition to the many negative impacts these psychosocial

challenges may have on an individual's immediate health, stigma can also pose as a major barrier to an individual's ability or desire to access care (Balderson et al., 2012; Brennan-Ing et al., 2013; Cahill & Caladez, 2013; Grov et al., 2010; Mill et al., 2009). Due to the many stereotypes and misconceptions regarding the sexuality of older adults, health education including HIV prevention rarely targets older populations. Cahill and Caladez (2013) have also found that, "health care providers tend not to assess older patients for sexual health related risks, regardless of sexual orientation and gender. A national study revealed that adults aged 50 years and older at risk for HIV were 80% less likely to be tested for HIV than were younger people" (p. e11). The barriers preventing older adults from being tested for HIV and from seeking medical treatment is an important issue that needs to be addressed immediately, due to the potentially life threatening implications. The psychosocial aspects of aging with HIV will be discussed in more detail in Chapter Three.

The older adult, HIV positive population is comprised of four groups: 1) People who have been HIV positive for many years, and who are now over 50 years of age, 2) People over 50 who have recently been infected and diagnosed with HIV, 3) People over 50 receiving a late diagnosis, but who were infected years before, and 4) People over 50 who are at risk of HIV and are unsure of their status. While each group will have their own set of unique issues, they will share common complications that are inherent to aging with HIV. Issues ranging from their diagnosis, ability to respond to treatment, disease and symptom management, morbidity, mortality and the ways in which service providers respond to their unique needs. While there is a growing body of literature on HIV and aging, the research tends to focus on the biomedical aspects of aging with HIV/AIDS, therefore, there is a dearth of information on the social aspects

of aging with HIV/AIDS (Roger et al., 2013; Sankar et al., 2011; Vance et al., 2008). Given what we know about the demographic trends in Canada specific to the Indigenous population with HIV, it is alarming that there is no literature on the social aspects of aging with HIV from an Indigenous perspective.

## **Indigenous Health & Wellbeing**

From an Indigenous worldview, disease is understood and approached in a very different manner from that of a western worldview (King et al., 2009). “The clashing of worldviews between the Western content-oriented, linear, and empirical worldview, and the First Nations process-oriented, nonlinear, and holistic worldview may explain the discrepancies in perceptions regarding time and the nature of health” (Hughes, 2006, p.11). Western, ‘allopathic’ approaches to health typically view health from the predominant, biomedical model which characterizes health as the absence of disease. Epidemiological approaches which target individual behavioral interventions may be successful in non-Indigenous populations. However, an epidemiological approach is not congruent with Indigenous epistemologies. Douglas (2013) explains that Indigenous epistemology sees the world as a unified whole, it values the collective over the individual. An epidemiological approach, does not provide the context which is necessary to gain a more comprehensive picture of health and illness. For many Indigenous people, health is far more broad and holistic. Health from an Indigenous perspective considers the spiritual, emotional, mental and physical well-being from not only an individual level but also a community level. Wilson and Rosenberg (2002) have described this Indigenous approach to health as ‘ecoepidemiological’, rather than the more common Western ‘epidemiological’

approach. Therefore, a more holistic approach to health, similar to an ‘ecoepidemiological’ incorporating social, cultural, historical, political and economic context needs to be considered when working with Indigenous peoples.

Discrepancies in respect to notions of health and disease coupled with the relatively new emergence of aging with HIV has resulted in a lack of culturally resonant information regarding successful aging for Indigenous peoples with HIV. Since culture greatly impacts the experience of disease (Cammer, 2006) lacking an understanding of the cultural beliefs that shape the experiences of Indigenous peoples aging with HIV makes it very difficult to provide culturally appropriate care for this population.

Ultimately, conventional scientific approaches are not congruent with Indigenous bodies of knowledge and epistemologies. Therefore, they will fall short in addressing the epidemic of HIV within this population. Indigenous peoples do not reject biomedicine, they too want the benefits that new health technologies have to offer; they just do not want the epistemology that accompanies it (Douglas, 2013). What is needed then is epistemological accommodation, which Douglas (2013) describes as a process where Indigenous patients and non-Indigenous health care providers accommodate and respect each other’s worldviews. Epistemological accommodation is necessary for the provision of culturally sensitive care. The knowledge of health scientists and Indigenous peoples needs to be considered equally valuable and relevant to the problem (Skinner, 2001). Without this recognition, Indigenous health research risks further perpetuating the cultural hegemony of Western knowledge over Indigenous knowledge. The use of Indigenous knowledge and decolonizing methodologies is one of the ways in which this thesis



employs epistemological accommodation. According to the Maori scholar, Linda Tuhiwai Smith, decolonization is concerned with having “a more critical understanding of the underlying assumptions, motivations and values that inform research practices” (1999). In academia, Western culture has emerged as the center of legitimate knowledge, which has been damaging particularly for Indigenous peoples given that Western knowledge, thus research, is embedded in colonial hegemony. Therefore, there is a need to decolonize the research process, especially with research involving Indigenous peoples. To successfully decolonize research, Indigenous peoples need to be involved in the process and a reflection on one’s own culture, values, assumptions and beliefs is critical throughout the research process.

### **Research Questions and Objectives**

Despite increasing evidence of the “greying of the epidemic” a federal response to this rapidly increasing, aging, HIV positive population is practically non-existent. Further research is needed to gain a better understanding of the lived experiences of the diverse population of older adults living with HIV/AIDS. This project was created in response to this knowledge, combined with CAAN member’s concerns regarding the lack of culturally mediated knowledge surrounding aging with HIV. Accordingly, the underlying research question guiding this project asks: what does health and wellbeing look like for Indigenous people aging with HIV? Furthermore, this research seeks to examine the coping mechanisms which enable this population to age successfully with HIV. Additionally, this research has taken a strengths based approach, highlighting the strengths and resiliency within the HIV positive, Indigenous population. While discussions about colonialism should be central to discussions about

Indigenous health, narratives about the strengths and resiliency of Indigenous peoples should be at the forefront. To continue to focus on the health inequalities and thus, negative health statistics, further perpetuates negative images of Indigenous peoples which already dominates mainstream consciousness. Moreover, such a focus undermines the current Indigenous Canadian landscape, which is one characterized by a resurgence in Indigenous cultures and healing (Wilson et al., 2011).

Consequently, the primary objectives of this research is to:

1. Identify culturally mediated responses to living well with HIV among older Indigenous peoples
2. Identify ways in which community and primary health services can structure themselves to promote successful aging with HIV in ways that are congruent with Indigenous culturally-defined notions of health and well-being
3. Take a strengths based approach, highlighting the strengths and resiliency within the HIV positive, Indigenous population
4. Develop a successful aging framework congruent with Indigenous defined notions of health, wellness and success.

Given that this project is embedded in a larger project on Indigenous peoples, aging with HIV, the secondary objective of this project is to:

1. Use the responses elucidated from these questions to narrow the research focus for a larger CIHR operating grant application (explained in the Methods section below), in order to ensure a community based research project is created based on the needs identified by this population

## **Reflexivity**

Given that I am a researcher, conducting community based Indigenous health research and I am not of Indigenous descent, it is important for me to clearly locate myself within the community of research. Abolson and Willett (2005) state that locating oneself in Indigenous community research means to provide details about where the researchers come from, their race and gender, who they are connected to, and what their research intentions are while in the community. I am a 24-year-old, Caucasian female of settler-colonial descent. My ancestors came from Scotland and Ireland and originally settled in Newfoundland, eventually moving to Nova Scotia. My grandfather was 16 when he left Nova Scotia, arriving in Hamilton, Ontario based on the prospect of work. My mother was born in Hamilton and subsequently, my three sisters and I were born in Hamilton. I have lived in Hamilton my whole life, only recently coming to recognize it as being on Haudenosaunee and Mississauga's of the New Credit territory. Acknowledging that I am not Indigenous and HIV negative, is important to me given that I am asking my participants to speak about their Indigenous identities and their positive HIV status. Furthermore, Abolson and Willett (2005) state that disclosing personal location facilitates trust, and increases communication between researchers and the Indigenous community members. As a result of this, Abolson and Willett (2005) state that the research results produced after the researcher's location has been disclosed are much more valid than other research results.

Locating myself in the community is extremely important to me given the history of Indigenous research in Canada. Indigenous peoples in Canada have all too often been

misrepresented throughout the research process, have had their knowledge appropriated, and research outcomes have commonly resulted in harm rather than benefits (Castleden, Sloan Morgan, & Neimanis, 2010). In fact, Smith (1999) as cited in Castleden, Sloan Morgan and Neimanis (2010) argues that, “Research is probably one of the dirtiest words in the Indigenous world’s vocabulary. When mentioned in many Indigenous contexts, it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful” (p. 1). Ultimately, by stating my location, I hope to assert my position in the research, allowing the research to be more subjective, credible, transparent and accountable. Furthermore, discussing location gives Indigenous peoples the ability to assert their self-determination, providing an opportunity to reclaim authority over their own knowledge (Absolson & Willet, 2005), thus, ensuring I do not perpetuate any harmful colonial ideologies.

It is also important to me to recognize the privilege my white settler-colonial status has afforded me, not only geographically and economically, but intellectually and academically. I recognize that due to the history of colonialism in this country many Indigenous peoples have been robbed of their traditions and cultures and equal opportunities for education. Consequently, many Indigenous peoples do not have access to much of the Indigenous knowledge that I have had the privilege of learning about. Furthermore, as a white decedent of settler-colonialism, I am extremely fortunate and grateful to be involved in this national project with the community organization, CAAN. As a result of my involvement, I have had the honour of learning from Indigenous peoples from all across Canada and the complete privilege to work with and learn from Indigenous Elders and Indigenous scholars in this field. Lastly, I want to acknowledge my privileged role in being able to contribute to decolonizing health research. I recognize that

Indigenous peoples lead the work in decolonization, non-Indigenous peoples cannot and should not. I am humbled to have had the opportunity to work on this project and I do not take this opportunity lightly.

## **Organization of Thesis**

Following the introduction, Chapter Two will elaborate on the successful aging framework which informed this research, Chapter Three presents a review of the relevant literature on the psychosocial aspects of aging with HIV/AIDS, which provides important context for this thesis. Chapter Four provides a description of the methods used to conduct this research, highlighting ethical considerations, data collection and analysis. Chapter Five combines a traditional results section which highlights the findings from this research with a discussion in order to establish the relationship between the data and the literature. To conclude, Chapter Six will provide an overview of major findings, and offer recommendations for future research.

## **Chapter Two: Theoretical Framework**

The theoretical framework used throughout this project, from its development through analysis and interpretation, is the successful aging framework. While there is no universal definition of successful aging, the MacArthur Network on Successful Aging, launched in 1984, operationalized three criteria of successful aging: (1) freedom from disease and disability, (2) high cognitive and physical functioning, and (3) active engagement with life (Martin et al., 2014). These criteria became the basis for the successful aging framework developed by Rowe and Kahn in 1997, which remains the most widely used conceptual framework in social gerontology today. This framework is testable by assessing older adult's ability to meet each criterion, thus being labeled as "successfully aging" (Martin et al., 2014). While this framework is the most widely used, it is not without controversy and criticism. Social gerontologist Matilda Riley was one of the first to critique Rowe and Kahn's model in a 1998 letter to the editor of the *Gerontologist*, calling the model "seriously incomplete" given its fixation on individual success and its absence for the consideration of structural and social factors which impact aging (as cited in Martinson and Berridge, 2015, p. 59). Liang and Luo (2012) highlight the irony of the dominance of the successful aging framework given that it is a discourse based on empirical data collected in America, yet it is continuously applied to many outside cultures without further reflection. Critiques of successful aging are plentiful, in fact, Martinson and Berridge (2015) identified 67 articles which included a critique of successful aging models. These critiques have been summarized into four categories: (1) 'The missing voices critique' (45% of critiques) highlights the need for greater consideration of the subjective nature of successful aging; (2) 'Add and stir' (25% of critiques) suggests additions to the model; (3) 'Hard hitting' (20% of

critiques) calls for a more inclusive definition of successful aging and an end to the discrimination against those not aging successfully; and (4) 'New frames and names' (10% of critiques), these criticisms try to correct or replace the perceived Western cultural bias in Rowe and Khan's model. It is important to point out that critics from all four of these categories highlighted the cultural bias inherent within the traditional model of successful aging.

As a result of the problematic nature of this widely used conceptual framework, more than 100 variations of the original model have been proposed. The majority of these variations include a focus on social factors influencing an individual's capacity to age successfully, the inclusion of a more subjective definition of successful aging, more emphasis placed on individual's perceptions of their own aging, and considerations of a cumulative advantages/disadvantages across the life course (Rowe & Khan, 2015). Out of these 100 or so variations, two successful aging frameworks which are particularly relevant to this study have emerged: (1) Selective Optimization with Compensation and (2) Preventive and Corrective Proactivity.

The Selective Optimization with Compensation model of successful aging was created in response to some of the common criticisms of Rowe and Khan's (1987) model. In response to Rowe and Khan's (1987) model, this model recognized the need to include multiple subjective and objective criteria, with particular emphasis on cultural variations with regards to the notion of success. Additionally, this model, created by Baltes and Baltes (1990) acknowledged physical and psychosocial losses due to aging, while focusing on remaining strengths and resources of older adults. The premise of this theory is that successful aging is a process that takes place

across the life course and includes three components: selection, optimization and compensation, and is testable if each component is properly operationalized (Martin et al., 2014). Selection implies that one's expectations can be adjusted to reach the subjective experience of satisfaction and self-control. Optimization refers to the process where people engage in behaviours to enrich and supplement their general reserves and to maximize their life trajectories in regard to quantity and quality. Compensation results from a decline in behavioral capacities, requiring older adults to adapt to these challenges using a combination of the mind and technology, for example, compensating for hearing loss by using a hearing aid (Baltes & Baltes, 1990). Ultimately, Selective Optimization with Compensation model of successful aging allows older adults to continue to engage in activities which are meaningful to them despite a decline in energy and/or biological and mental reserves. Baltes and Baltes (1990) recognize that with "each case of successful aging, there is likely to be a creative, individualized, and societally appropriate combination of selection, optimization, and compensation" (p.26). This model is of particular importance because it not only recognizes the lack of cultural breadth and subjective meanings of successful aging, but it attempts to address these limitations by suggesting a model which allows for subjectivity and thus, differences in cultural interpretations of social phenomena.

The Preventive and Corrective Proactivity model of successful aging was developed by Kahana and Kahana (1996) to be more inclusive of the older population living with physical, social, and environmental challenges who were also aging successfully. This model is based on stress-theory, recognizing that older adults commonly face normative stressors such as chronic illness, social losses and a decrease in person-environment fit. Despite these stressors, this framework focuses on the potential to maintain a good quality of life through the use of internal



coping resources and external social resources. Kahana and Kahana (1996) believe that, “such resources can translate into proactive behavioral adaptations that include health promotion, helping others, and planning ahead (preventive adaptations), along with marshalling support, role substitution, and environmental modifications (corrective adaptations). Such proactive adaptations can help ameliorate the adverse effects of stressors on quality of life outcomes, such as psychological well-being, goals, and meaning in life, and maintenance of valued activities and relationships” (as cited in Martin et al., 2014, pg. 6). Kahana and Kahana (2001) and Emlet, Tozay and Raveis (2011) have successfully applied this model to older adults living with HIV/AIDS. This is important, because prior to the development of this model, vulnerable populations of older adults such as those living with HIV/AIDS would not be able to be considered successful agers. In fact, because of the dominance of Rowe and Khan’s (1997) model of successful aging, older adults with chronic and infectious conditions are often still excluded from discussions around successful aging.

While both the Selective Optimization with Compensation and Preventive and Corrective Proactivity models of successful aging represent much needed additions to the successful aging discourse, neither are widely used models. Consequently, Rowe and Khan’s (1997) model of successful aging still prevails. While the cultural bias within this framework is recognized and its applicability to non-Western culture’s is questioned, there is a lack of dialogue on the successful aging frameworks applicability to Indigenous cultures. We do know that successful aging models are value laden and given the epistemological and ontological differences between Western and Indigenous cultures it is easy to see how traditional models of successful aging would not be congruent with Indigenous perceptions of what it means to age successfully. For example,

traditional successful aging models have been described as creating a “disharmony between body and mind” (Liang & Luo, 2012, p.4) which is very problematic given that within Indigenous understandings of health and wellness the body and mind cannot be separated. Indigenous notions of health and wellness and alternatively, disease, are understood and viewed differently from that of a Western worldview (King et al, 2009). Since culture greatly impacts the experience of health and illness, lacking an understanding of Indigenous cultural beliefs about successful aging makes it very challenging to provide care and create policies in ways which can promote successful aging. Therefore, in order to suggest, create, or recommend an Indigenous model of successful aging, a more holistic and nuanced understanding of how Indigenous peoples living with HIV understand successful aging is essential.

What we learned from this sample of older Indigenous, HIV positive people is that these individuals did not dichotomize themselves or other’s into “successful” and “unsuccessful” agers. The creation of a binary of successful and unsuccessful aging is a common consequence of traditional successful aging models and is said to result in a new form of ageism (Martinson & Berridge, 2015). While this binary of successful and unsuccessful is common within traditional models of successful aging and more specifically, Western cultures, this was not a result of this study. Participants did not equate challenges such as having HIV, mobility constraints, the loss of a limb, low income, addictions or lack of employment as factors that disqualified themselves or someone else from being able to age successfully. Rather, these individuals focused on their strengths and things that they were gaining such as: clarity, wisdom, improved relationships with family and friends, spiritual and cultural knowledge, resilience, purpose and direction in life and self-determination as factors which contributed to their ability to age successfully. Perhaps this

distinction is the result of differences in beliefs about aging between Indigenous and Western cultures. Western culture has become obsessed with prolonging youth and thereby delaying death, whereas Indigenous peoples such as the Iroquois take pleasure in aging because old age represents a time where one is held in high esteem. Furthermore, the older years are commonly understood as a time where an individual can pass on their life experiences (George-Kanentiio, 2000). Indigenous cultures ability to embrace aging rather than attempting to delay the process may in and of itself be a contributing factor to this population's ability to age successfully despite many obstacles.

Where traditional models of successful aging strive to be measurable and testable, an Indigenous model can be based on experience and direct participation with the natural world. Successful aging should be viewed as a process with no endpoint, it is a journey which takes place across the life course. Central to these Indigenous people's abilities to age successfully is finding a balance between spiritual, emotional, mental, social and physical dimensions of health. Successful aging should be about a process of holistically healing oneself, rather than a harmful path of trying to achieve normative ideals of aging which are often unrealistic if not completely unattainable. This process of finding one's balance should be empowering rather than discouraging.

While the traditional successful aging framework represents a normative ideal which lacks consideration of macro social structural conditions (Martinson & Berridge, 2015) an Indigenous model of successful aging proposed in this research considers these macro social structural conditions that this population experiences, allowing for "success" regardless of one's

social location. Traditional models of successful aging which continue to focus on individual success undermine the impact that social and structural factors such as race, class, gender, and ability has on an individual's health and therefore, their ability to age successfully. Recognition of the personal, political, social and economic contexts of aging should be fundamental components of a successful aging framework. Ultimately, this model represents a more holistic, inclusive and culturally relevant framework, where one's ability to "age successfully" is far more attainable than the traditional successful aging model developed by Rowe and Kahn (1997).

While more literature is needed on aging with HIV/AIDS and greater consideration of successful aging with HIV/AIDS, specifically from an Indigenous lens, we need to acknowledge that there is no one ideal way of aging between cultures, or even within cultures. Martinson and Berridge (2015) suggest that creating ideal models of aging is destructive and serves to devalue the diversity in views on aging. Given that the Indigenous model proposed in this project does not describe an unattainable ideal of aging, or suggest a need or way to measure and test individual's abilities to age successfully, this model should not contribute to the further harm and marginalization of older Indigenous peoples. Alternatively, this model merely demonstrates a journey which individuals in this study are currently on, attempting to find and/or maintain a balance necessary to achieve successful aging. This journey is recognized as being an extremely subjective process with no standardized approach or measurable outcome. Undertaking this journey could be viewed as successful aging itself. Ultimately, successful aging should be more about the process and not the outcome. The process should be healing and empowering, and if presented this way should leave little room for harm.

Self-determination is inherent to this model and self-determination should be a central component to Indigenous health research and healing approaches. According to Daes (1996), “Self-determination encompasses social, cultural, economic and political aspirations and refers to the inherent right of indigenous peoples to govern their own affairs as original occupants, through the reform of relations with settler governments” (as cited in Walker, 2008, p.191). Furthermore, the Royal Commission on Aboriginal Peoples (1996) recognized that, “self-determination is an important element in achieving self-reliance, that a greater degree of autonomy in the political realm is illusory without a strong economic base, and that both these elements will contribute to and be nourished by the process of healing” (p.662). Self-determination is important because it allows participants to gain a sense of ownership and assert autonomy over their own learning and empowerment in the determination of the direction of their individual and community’s collective healing. Indigenizing the successful aging model is an important step to decolonizing the field and decolonization is foundational to Indigenous health and wellness. Additionally, Indigenizing the successful aging framework is one way to minimize the harm that comes from the creation and subsequent promotion of ideal norms of aging which are typically unattainable to the average person and likely even more unattainable to an Indigenous person due to differences in cultural perceptions and beliefs surrounding health and aging. For these reasons, this research sought to create an Indigenous specific model of successful aging (see Appendix D), this model will be discussed in more detail in Chapter Five.

## Chapter Three: Literature Review

### Introduction

The year 2015 signaled a new period in the HIV/AIDS epidemic. For the first time in the history of the epidemic, it has been said that more than 50% of people living with HIV/AIDS in the United States of America are over the age of 50 (Brennan, Emlet & Eady; 2011; Ellman et al., 2014; Hansen et al., 2013; Jang, Anderson & Menten, 2011). While the prevalence of HIV within this cohort of “older adults” is not quite as high in Canada, there is evidence that the aging of the HIV/AIDS epidemic is a global phenomenon. This phenomenon has been characterized by some, as the “greying of the HIV/AIDS epidemic” (Beaulaurier, Craig & De La Rosa, 2009; Beuthin, Bruce & Shields, 2015; Emlet & Shippy, 2008; Grov et al., 2010; Haile, Padilla & Parker, 2011; Mueller, 1997; Nevedal & Sankar, 2015; Orel, Stelle & Watson, 2008; Stormholm et al., 2013). The greying of the epidemic has been largely attributed to increases in longevity as a result of the success of antiretroviral treatments (ART) and slightly less so to the fact that older adults are beginning to comprise a larger proportion of those newly diagnosed with HIV (Balderson et al., 2013; Brennan, 2008; Cahill & Caladez, 2013; Ellman et al., 2014; Foster & Gaskins, 2009; Heckman et al., 2002; Owen & Catalan, 2012; Psaros et al., 2015; Roger, Mignone & Kirkland, 2013; Siconolfi et al., 2013; Siemon et al., 2013; Solomon et al., 2014; Stormholm et al., 2013; Vance, Struzick & Childs, 2010; Wallach & Brotman, 2013). Therefore the aging, HIV positive population is comprised of two groups: those over the age of 50, newly diagnosed with HIV and those living with HIV who have aged into their 50’s. Many studies address the fact that the experiences of those aging with HIV is very different from those who acquire HIV in their later years (Ellman et al., 2014; Orchi et al., 2008; Ory et al., 1998;

Robinson et al., 2008). While there is a growing body of literature in this area, the research tends to focus on the biomedical aspects of aging with HIV/AIDS, therefore, there is a dearth of information on the social aspects of aging with HIV/AIDS (Roger et al., 2013; Sankar et al., 2011; Vance et al., 2008). As a result, a literature review on the social aspects of aging with HIV was conducted.

A rapid literature review which uses accelerated or streamlined methods in comparison to traditional systematic reviews (Ganann, Ciliska, & Thomas 2010) was conducted on the social aspects of aging in relation to Indigenous peoples with HIV/AIDS. The search was conducted between May and July of 2015 to identify relevant academic journal articles. Sociological Abstracts, PsycINFO, AgeLine and Scholars Portal, were the electronic databases that were used for this search. These electronic databases were selected based on consultation with a McMaster University librarian. The following key terms were searched in various combinations: Aboriginal\*, Aborigine\*, Indigenous, native\*, "first nation\*", "first-nation\*", "1st nation\*", "1st-nation\*", Indian\*, Amerindian\*, tribal, autochtone\*, Amerindien\*, Aborigene, Indigene\*, and HIV, HIV positive, HIV-positive, HIV/AIDS, AIDS, HIV and AIDS, Living with HIV, Living with AIDS, Living with HIV/AIDS, HIV affected, and aging, aged, longevity, older adult\*, senior, young old. The terms which were used to search for literature specific to Indigenous peoples were chosen to be inclusive of the global Indigenous population. These search terms were selected in consultation with thesis committee members Randy Jackson and Dr. Chelsea Gabel. The decision to expand the search to be inclusive of the global Indigenous population rather than a Canadian specific or North American Indigenous population was in response to the paucity of literature on the social aspects of aging with HIV/AIDS in general (Roger et al, 2013),

and the apparent absence of literature in this area specific to Indigenous peoples. Shortly after the search was expanded to be representative of the global Indigenous population, it was evident that no such literature existed, be it on the North American Indigenous population or on the global Indigenous population. Therefore, a search was conducted on the social aspects of aging with HIV/AIDS.

The following questions were used as inclusion criteria to screen the studies yielded from the above searches: (1) Does the article include a focus on the social aspects of aging with HIV/AIDS? (2) Does some component or this entire article focus on the 50+ population living with HIV? (3) Does this article address either older adults living long term with HIV and/or those diagnosed over the age of 50? (4) Was the data in this article collected  $\geq 1996$  (post introduction of HAART)? (5) Does the article include a focus on Indigenous peoples or include Indigenous participants? Journal articles were excluded if they did not meet inclusion criteria 1-4. A note was made if the article met the 5<sup>th</sup> inclusion criterion.

Searching the key terms listed above on Scholar's Portal yielded 5986 results, AgeLine on Ebsco yielded 763 results, and Sociological and PsycINFO Abstracts on Proquest yielded 668 results. In total 7417 abstracts were read through. Out of these 7417 articles only 200 were identified as meeting the inclusion criteria listed above. The abstracts of these 200 articles were compiled into a word document and sent to thesis committee members, Randy Jackson, and Dr. Chelsea Gabel, for further consideration of whether or not the articles should be included. Upon further investigation 64 out of the 200 articles were found to not meet all of the inclusion criteria. We also came to a collective decision to exclude articles which focused solely on



service provision, service utilization and prevention. The remaining 136 articles were read using an open analytic approach to explore the content of the literature and to draw themes from the text. During this phase an additional 34 articles were flagged as not meeting some of the inclusion criterion and/or were too heavily focused on service provision, service utilization and/or prevention. Once all members agreed, these 34 articles were excluded, resulting in a total of 102 articles included in the literature review.

Throughout the open analytic process used to explore the literature, several common themes emerged. These themes and key passages were collectively analyzed between myself Randy Jackson and Chelsea Gabel in order to come up with larger conceptual categories which were found to emerge from the text. These categories were actively reviewed and revised using an inductive and iterative process and passages that contradicted the themes were sought out. Each of these themes are detailed in the literature review section below.

## **Global Perspective**

The majority of articles focus on the phenomenon of aging and HIV within a North American context, specifically within the United States of America and a few studies in Canada. A handful of articles examine this phenomenon from a European, African and Asian context, with studies conducted in: The United Kingdom, Italy, Uganda, Togo, South Africa, Thailand and India. These findings may be reflective of the fact that the “greying of the epidemic” has had the greatest impact in the United States, thus far. For example, America is the only country to report that as of 2015 more than 50 percent of the people living with HIV/AIDS (PHA)

population is over the age of 50. The “greying of the epidemic” in North America and Europe is well documented. Whereas, statistics collected from the World Health Organization in 1999 reported that people aged 50 plus made up 5.6 percent of all AIDS cases in Africa, 4.5 percent in Asia and 7.4 percent in Latin America, demonstrating a much lower rate of AIDS cases among older adults in these less developed regions (Wallach & Brotman, 2013).

Ellman et al. (2014) stated that, “as of 2011 persons aged 50 and older comprised 17% of new HIV diagnoses and 25% of all AIDS diagnoses in the United States” (p.530). Furthermore, it has been found that, “although general numbers of AIDS cases in Canada have decreased over time, the proportion of AIDS cases among people aged 50 years and older has actually increased, from 16 per cent in 1999 to 22 per cent in 2008” (Furlotte et al., 2012, p. 38). While these findings clearly illustrate the impact the epidemic is having on the aging population in North America, Elford and colleagues (2008) point out that there has been a twofold increase in PHA’s over 50 in the UK since the advent of highly active antiretroviral therapy (HAART). This finding demonstrates that the greying of the epidemic is not a phenomenon unique to North America.

While there is no question that the epidemic has had a major impact in the United States, the greatest epidemic has been felt internationally (Sankar et al., 1998). While the percentage of older PHA’s in the East isn’t quite as large as the West, it has been estimated that roughly 3 million PHA’s are over the age of 50 in sub-Saharan Africa (Moore, 2012). Despite these findings, very little research is available on aging and HIV in the East. Cahill and Valadez (2013) state that PHA’s from developed nations who begin HAART at an initial CD4 count above 200 can age into their 70’s. Unfortunately, these increases in longevity have not been experienced by

PHA's in the East. In their study, Nyirenda et al (2012) reported that the life expectancy for Ugandans is 54 years and 52 years for South Africans. These poor life expectancies can be attributed to poorer access to efficient HIV treatments (Wallach & Brotman, 2013) leading to high rates of HIV mortality (Nyirenda et al., 2012). In order to grasp the social impacts of HIV/AIDS, cross-cultural perspectives are imperative.

This type of approach is of particular importance in HIV/AIDS research due to the fact that, cultural values, beliefs, and practices are explicitly implicated in the spread and experience of the epidemic and, conversely, the epidemic is affecting the practice of cultures. Cultural practices related to community and family integration become strained and shifts occur in normative role relationships between multiple generations (Sankar et al., 1998).

In addition to culture, gender and race will without a doubt shape how people age with HIV (Vance & Robinson, 2004). Thus, the experience of aging with HIV will be examined from a racial/ethnic and gender specific lens below.

### **Race and Ethnicity**

The interactions between age, race and HIV are yet to be fully understood (Vance & Robinson, 2004). However, we do know that racial and ethnic disparities are prevalent within the HIV positive population. Similar to the demographics of younger adults with HIV, older adults of ethnic minorities are disproportionately affected by HIV/AIDS (Brown & Sankar, 1998; Crisologo et al., 1996; Emler & Shippey, 2008; Golub, 2013; Stormholm et al., 2013; Waysdorf, 2002). Ellman et al. (2014) goes one step further and states that the disparities which exist between race and ethnicity are more extreme in older PHA's than in the population of younger PHA's. Similar to younger PHA's, in the United States of America, African Americans and Hispanics are disproportionately affected, whereas in Canada, the Aboriginal population is

disproportionately affected (Brennan et al., 2011; Ellman et al., 2014; Stormholm et al., 2013). More specifically, within the United States of America, HIV/AIDS rates in older adults are 12 times higher for African Americans than they are for Caucasians (Foster & Gaskins, 2009). Furthermore, Levy-Dweck (2005) estimates that roughly 52 percent of older PHA's in America are either African American or Hispanic/Latino. Between the years 1998-2002, AIDS incidences in the United States declined among Whites and Hispanics, however, there was an increase among, blacks, Asian/Pacific Islanders, and American Indians/Alaskan Natives (Levy-Dweck, 2005). These findings clearly illustrate the "racialization of the epidemic" (Haile et al., 2011, p. 2). Similar racial and ethnic disparities exist within Europe as well. According to Elford et al. (2008) gay men and black African heterosexual men and women are disproportionately affected in the United Kingdom, making up 80% of the HIV positive population. Ory et al. (1998) describes how "older Americans of colour are affected by the epidemic in myriad ways because of subcultural and historical experiences with the medical establishment and their disproportionate experience with poverty" (p.643).

All of these trends are part of a larger pattern which has been described as the social gradient of health, which is that HIV/AIDS disproportionately affects minority racial/ethnic groups as well as the poor (Haile et al., 2011; Levy-Dweck, 2005; Stormholm et al., 2013). Brown and Sankar (1998) and Stormholm et al. (2013) have used the double jeopardy hypothesis to highlight the intersecting disadvantages of race and age to explain the higher incidence and mortality rates of HIV/AIDS among older minority persons in comparison to their white counterparts. According to Emlet (2004) "older adults from ethnic minority communities have been found to possess lower levels of knowledge about HIV/AIDS as compared to their White

counterparts of the same age. Additionally, stigma associated with HIV among people of colour may be a significant barrier to prevention, education and testing” (p.3). Ultimately, older minority adults living with HIV will continue to encounter confounding intersections of racism, ageism and HIV stigma until these disparities are addressed (Emlet, 2004).

A number of studies have highlighted the importance of informal social support in the lives of older adults from ethnic minority communities. However, it has been found in a few studies that both Hispanic and African Americans received significantly less informal social support from a variety of sources such as, family, friends, and religious congregations (Emlet, 2004). This is problematic given the importance of social support to an older adult’s wellbeing. Moreover, while the social support networks of older adults of ethnic minorities may be damaged due to HIV stigma, they also encounter barriers in accessing formal care and treatment (Emlet, 2004).

## **Gender:**

### ***Men***

According to Brennan (2008) older men represent one of the fastest growing segments of people living with the condition. This finding should not come as a surprise given that since the inception of the epidemic, men have been disproportionately affected, at least within North America and Europe. Within the population of HIV positive men, men who have sex with men represent the greatest percentage of those who have been affected by the disease. Throughout the beginning of the epidemic, HIV/AIDS, was conceptualized as the “gay man’s” disease and initially referred to as GRID “Gay-related Immune Deficiency” (Cahill & Valadez, 2013;

Mueller, 1997; Wooten-Bielski, 1999; Zablotsky, 1998). Rosenfeld, Bartlam and Smith (2012) have stated that,

Regardless of HIV status, all gay male Baby Boomers are aging in a context strongly shaped by HIV/AIDS. For this sub-cohort within the Baby Boom generation, the disproportionately high volume of AIDS deaths among gay men aged 25-44 years at the epidemic's peak (1987-1996) created a cohort effect, decimating their social networks and shaping their personal and social lives during the epidemic, throughout their life course, and into later years (p. 1).

As this quote demonstrates, older gay men with HIV have been significantly impacted by the epidemic, consequently, older, gay men with HIV are more likely to be socially isolated and emotionally depleted from the loss of partners and friends to AIDS (Cahill & Valadez, 2013; Owen & Catalan, 2012; Robinson et al., 2008; Rosenfeld et al., 2012; Schrimshaw & Siegel, 2003). In addition, Brennan (2008) found that heterosexual and homosexual men with HIV may experience discrimination from conservative religious communities due to the misconception of HIV as a "gay" disease. Furthermore, he found that this type of discrimination may result in psychological distress among heterosexual and homosexual men with HIV (Brennan, 2008). This is concerning given the importance of social support on an individual's health and wellbeing and the current prevalence of older HIV positive men.

In the United States, the majority of individuals living with HIV are men who have sex with men (MSM), this pattern is also present in the 50 + age group (Emler, 2004; Hampton et al., 2013). As a result of the epidemic's impact on MSM there appears to be limited knowledge on heterosexual men's experiences of aging with HIV. Most studies have focused on younger, gay, white men, since they were the first group to be heavily impacted by the epidemic (Shippy & Karpiak, 2005). Likewise, due to society's perception of older adults as sexually inactive there is very little information and few services which recognize the association between HIV and aging,

particularly among aging gay men (Crisologo et al., 1996; Robinson et al., 2008; Wooten-Bielski, 1999).

The “racialization” of the epidemic is also evident within the HIV positive population of MSM (Haile et al., 2011). According to the CDC the prevalence of HIV among black MSM in urban settings is estimated at 46 percent, additionally in a five-year period spanning from 2001 to 2006, HIV diagnoses were twice as high in black MSM in comparison to their white counterparts (Haile et al., 2011). Regardless of sexual orientation, race, gender, and age, men continue to make up the largest proportion of those diagnosed with HIV in the U.S. (Emlet & Shippy, 2008).

### ***Women***

While men make up the largest proportion of those infected, the greatest rise in geriatric AIDS cases has been among women, and older adults of colour, particularly African Americans (Waysdorf, 2002). More specifically, women of colour make up 70 percent of the 50+ population living with HIV/AIDS in America (Levy-Dweck, 2005). Older Latina women represent one of the fastest growing segments of the older, HIV positive population (Beaulaurier et al., 2009). The Public Health Agency of Canada (2010) reported that Indigenous women over the age of 40 represented 38 percent of all AIDS cases reported by ethnicity from 1998 to 2009 (Roget et al., 2013). Thus, it appears that older women of colour are doubly impacted due to their gender and race/ethnicity.

It is estimated by the Centers for Disease Control (CDC) that two-thirds of all women in the 50 plus age category who contract AIDS are exposed through heterosexual contact (Beaulaurier et al., 2009). Physiological changes place women at higher risk than men to contract the virus through heterosexual contact. In fact, women are 12 times more likely than men to become infected with HIV through heterosexual contact (Brennan et al., 2011). In addition to these gender and racial/ethnic specific vulnerabilities, older women also experience physiological vulnerabilities based on their age. For example, as a result of changes to a woman's hormone levels throughout and post menopause, a thinning of the vaginal mucosa occurs and vaginal tissue becomes dryer, which increases risk of vaginal tearing during intercourse, thus increasing the risk of viral entry (Beaulaurier et al., 2009; Brennan et al., 2011; Crisologo et al., 1996; Emlet, 2004; Szirony, 1999; Emlet, 2004). Furthermore, the aging process weakens the body's immune response, which can result in the rapid progression of HIV to AIDS (Beaulaurier et al., 2009; Brennan et al., 2011; Crisologo et al., 1996; Emlet, 2004; Goodroad, 2003; Waysdorf, 2002; Wooten-Bielski, 1999). This knowledge is alarming in and of itself and combined with research that shows that older women waive the use of condoms during sexual intercourse because they are no longer at risk for pregnancy, it is increasingly troublesome (Crisologo et al., 1996; Emlet & Farkas, 2001; Beaulaurier et al., 2009; Mueller, 1997; Schable et al., 1996). Even more alarming is that health care professionals also perceive older adults to be at low risk for sexually transmitted infections and blood borne illnesses, so there are lower rates of health prevention practices, testing, misdiagnosis of symptoms and consequently, late diagnoses (Emlet & Farkas, 2001; Beaulaurier et al., 2009; Brennan et al., 2011; Schable et al., 1996; Shippy & Karpiak, 2005; Szirony, 1999; Wooten-Bielski, 1999). Additionally, because HIV was originally characterized as a disease only affecting gay men, and the disease continues



to disproportionately impact men, the needs of other populations, including but not limited to, older women are commonly over looked (Brennan et al., 2011; Emlet, 2004; Mueller, 1997; Zablotsky, 1998). As a result, many older women are uninformed about their HIV/AIDS risk (Emlet, 2014; Zablotsky, 1998).

Older women are doubly disadvantaged because of the simultaneous exclusion of both women and older adults from HIV/AIDS research and interventions (Emlet & Farkas, 2001; Zablotsky, 1998). According to Emlet (2014) “older women living with HIV are often invisible due to myths about aging, sexuality, and risk” (p. 146). Ultimately, women face many barriers to access testing and treatment for HIV, based on their age, physiology, ageist perceptions about sexual activity and race and ethnicity which are further compounded by their gender.

### **Psychosocial health:**

In addition to the physical health challenges related to aging with HIV/AIDS, PHA’s commonly experience a variety of psychosocial challenges such as; stigma, social support, social isolation and depression. While these psychosocial issues are common within the general population living with HIV, it has been said that for older adults, these psychosocial stressors may be intensified due to interactions with the aging process (Emlet & Farkas, 2001; Grov et al., 2010; Heckman et al., 2000).

## *Stigma*

Experiences of stigma can have detrimental consequences on older PHA's. For example, "stigma can make people less likely to seek an HIV test, less likely to disclose HIV status if they are positive, and more likely to engage in high risk behaviours" (Cahill & Valadez, 2013, p. e10). Furthermore, fear of stigma negatively affects individual's quality of life and the ways in which they seek care, which can result in an increase of susceptibility and vulnerability to HIV infection (Cahill & Valadez, 2013; Foster & Gaskin, 2009; Kuteesa et al., 2014).

In the literature the idea of "double stigma" experienced by older PHA's is commonly cited, and has been described as the interaction of HIV stigma with ageism (Emlet, 2006; Kutessa et al., 2014, Solomon et al., 2014; Stormholm et al., 2013). Interestingly, in Foster and Gaskins (2009) study, participants thought that their experience with stigma was not compounded by their age. However, this does not seem to be the norm. Some studies have went further, discussing "triple stigma" experienced by older PHA's, that is ageism as well as the misconception about HIV/AIDS and anti-gay prejudice (Cahill & Valadez, 2013, p.e10). Furthermore, Stormholm et al. (2013) and Emlet (2006) have both addressed the fact that notions of double or even triple stigma underscore the importance of the impact that multiple stigmatizing identities have on the lives of older PHA's. HIV related stigma often overlaps with other forms of stigma such as sexism, racism, homophobia, ableism, ageism and stigma related to minority status (Storholm et al., 2013). In Siemon and colleagues (2013) study on social participation among women living with HIV, it was found that women experienced stigma based on their culture, gender, sexual orientation, HIV status and age. This experience however, is not

unique to women. Also according to Siemon et al. (2013) “this finding goes beyond the double jeopardy or triple jeopardy reported in the literature and points to the need for widespread intervention and education to reduce stigma experienced by older women living with HIV” (p.248). In their study, Stormholm et al. (2013) found that participants with a greater number of minority burdens experience greater HIV related stigma which is associated with a higher mental health burden. This is demonstrated by a finding from Grov et al.’s (2010) study which stated that, “higher rates of HIV stigma, and loneliness place older adults at increased risk for major depressive symptoms” (p. 637). These findings have significant implications for the mental health of older PHA’s with multiple stigmatizing identities.

In addition to the many negative impacts stigma may have on an individual’s immediate health, stigma can also pose as a major barrier to accessing care (Cahill & Valadez, 2013). Many studies describe older PHA’s dissatisfaction with their encounters with AIDS Service Organizations (ASO), service providers, mainstream health care institutions and health care professionals. This is due to the ageism they encounter at ASO’s and the HIV stigma encountered at mainstream health care facilities including nursing homes. Genke (2000) describes older PHA’s as just not “fitting in” anywhere because,

They are uncomfortable in mainstream aging networks where their issues are ignored or denied, and where they feel compelled to conceal their condition from morally judgmental contemporaries. They are just as uncomfortable in the HIV/AIDS arena, which focuses on a younger population generally, and where they confront many of the “social outcasts” with whom they are grouped and yet do not identify (p.204).

## *Disclosure*

The literature suggests that due to high levels of stigma related to HIV status and age, older adults are less likely than their younger counterparts to disclose their status (Emlet, 2006; Emlet 2007; Grov et al., 2010; Kutessa et al., 2014; Nokes et al., 2000). Emlet (2008) found that reasons surrounding disclosure found in younger PHA's such as a concern about being stigmatized, rejected and discriminated against was similar for older PHA's. Despite these findings, Kuteesa et al.'s (2014) study on HIV stigma in older PHA's in Uganda, reported that participants did experience a considerable amount of stigma, however, about two-thirds disclosed their status often or very often within and outside of their families. Similarly, in a study by Poindexter and Shippy (2010) more than a third of the participants had disclosed their HIV status and were found to be resisting the stigma. In a study on the personal networks and disclosure of older PHA's in Togo, Moore (2012) found that differences in rates of disclosure could be explained by the needs of older PHA's and further, who could help them meet those needs. For example, most participants disclosed their status to people that could lend them a significant amount of money. According to Moore (2012) older PHA's, "weigh the costs and benefits of disclosure to significant others and sexual partners because the consequences of disclosure of one's positive sero-status may be potentially harmful" (p. 228). Perhaps, this cost-benefit analysis hypothesis could be extended to older PHA's in the West as well.

## ***Social Participation***

Social participation can be best understood along a continuum which ranges from social engagement to social isolation (Siemon et al., 2013). Social support networks have been consistently acknowledged as an important element in the lives of people with HIV/AIDS. Often, social participation is used as an indicator of wellbeing. Social support has been found to mitigate HIV distress, positively impacting individual's moods and distress levels (Sankar et al., 2011; Schrimshaw & Siegel, 2003). While the benefits of social engagement and support in the lives of older PHA's are well known, social isolation within the older PHA population is common (Bhavan et al., 2008; Emler 2006; Meadows et al., 1998; Shippy & Karpiak, 2005; Siemon et al., 2013; Siegel, Raveis & Kraus, 1998). For example, Solomon et al., (2013) point out how social isolation is a risk factor for the general aging population, so older adults with HIV are at an even greater risk for social isolation and depression. In fact, Brennan-Ing et al. (2013) concludes that older adults with HIV experience endemic social isolation and stigma. However, in another study, Nokes et al. (2000) found that older PHA's did not perceive themselves to have less support than their younger counterparts. Despite this finding, many studies have indicated that older PHA's are more likely to be isolated in comparison to younger PHA's (Emler 2006; Emler & Farkas, 2002). It is also known that older adults with HIV/AIDS are more likely to live alone than their younger counterparts (Emler & Farkas, 2001). These trends suggest that older PHA's may be at an elevated risk of social isolation.

## *Depression*

Despite findings which suggest higher levels of stigma in the older PHA population than the younger PHA population, many studies comparing the rates of depression between older and younger PHA's found no significant differences (Meadows, 1998; Nokes, 2000; Orchi et al., 2008; Schrimshaw & Siegel, 2000). An exception to this is a study by Heckman et al. (1999) which did find older PHA's experienced greater levels of depression than younger PHA's. Additionally, Schrimshaw and Siegel (2000) postulated that, "although older infected adults (50+) have not been found to be more depressed than younger adults with HIV/AIDS, they (like younger adults with HIV/AIDS) are at significant risk for depression" (p. 739). Heckman et al. (2002) reported that many older PHA's in their study reported a high number of depressive symptoms which has been linked to unsafe sexual behaviours. Additionally, Grov et al. (2010) examines the issues regarding depression and HIV related stigma, finding that it can adversely impact an individual's adherence to treatment. Furthermore, Skalski et al. (2013) reported that there was an elevated risk of drug use amongst older PHA's experiencing depression. Thus, the impact of depression on the lives of older PHA's have far reaching implications.

There are a few studies that have all found older PHA's to experience depression and suicidal ideation at greater rates than the general population (Balderson et al., 2013; Grov et al., 2010; Heckman et al., 2002; Kalichman et al., 2000; Vance, 2006; Vance et al., 2010). HIV positive men appear to be at greater risk of suicide than their female counterparts (Kalichman et al., 2000). In their study on depression and thoughts of suicide among middle-aged and older adults living with HIV/AIDS, Kalichman et al. (2000) reported that participants who had thought

about suicide experienced higher levels of depression than their counterparts. Additionally, they found suicidal ideation was most prevalent within their white, male participants identifying as gay. Given that social isolation has been linked to depression, it is not surprising that their study also found that participants who thought about suicide perceived themselves as receiving less social support than those who did not (Kalichman et al., 2000).

### *Successful Aging*

While much of the literature examines the challenges associated with aging with HIV/AIDS, a handful of articles highlight the resiliency of older PHA's and their abilities to cope. A study conducted by Siegel et al. (1998) appears to be the earliest research which looked at the strengths of older PHA's. Participants in their study spoke about advantages they perceived in being an older adult with HIV/AIDS. Siegel et al. (1998) found that "most notable were the emphasis on the value of wisdom and enhanced problem solving abilities that were believed to accompany aging" (p.705). Emlet et al. (2013) found that as individuals live longer with HIV, it may become less of a focus on their life and thus, less internalized. Therefore, it is possible that individuals living long term with HIV develop vital stigma management strategies, enhancing their quality of life and obtaining a level of successful aging (Emlet et al., 2011, Emlet et al., 2013; Psaros et al., 2015). Psaros et al. (2015) found that concepts such as resilience, optimism and problem focused coping are essential to successful aging. Throughout the literature, a number of protective factors for aging with HIV were identified. These include: social support (Hansen, 2013; Owen & Catalan, 2012; Poindexter, 2004), acceptance of the disease and oneself (Emlet et al., 2010; Foster & Gaskins, 2009), generativity (Emlet et al., 2010;

Owen and Catalan, 2012; Poindexter, 2004; Sankar et al., 2010), self-esteem (Beuthin et al., 2015), spirituality (Brennan, 2008; Siegel & Schrimshaw, 2002; Hampton et al., 2013) and drawing on cultural resources (Sankar et al., 2011).

Kahana and Kahana (2001) developed a model of successful aging which was applicable to adults aging with chronic, debilitating, and life threatening conditions such as HIV/AIDS. This model suggests using psychological and social outcomes as measures of high quality of life rather than the traditional measures of absence of disease and maintaining high levels of mental and physical functioning (Kahana & Kahana, 2001). Emlet et al. (2010) support Kahana and Kahana's (2001) Preventative-Corrective Proactivity (PCP) model of Successful Aging. Vance and Robinson (2004) identify cognitive efficiency, hardiness, and a "can do" attitude as psychological components of successful aging. In addition, they identify social support and financial wellbeing as social components necessary for successful aging. Lastly, they discuss the importance of mobility, autonomy, and minimal disease as physical components which contribute to successful aging. Vance, Struzick and Masten (2008) discuss the importance of hardiness in aging with HIV, concluding that it can mitigate aging and HIV-related decline. Further research is needed to build on the current findings regarding the resiliency which already exists within the older PHA population in order to translate these findings into strategies to help others with HIV to age successfully.



## **Sexual Health:**

### ***Stereotypes***

HIV has typically been viewed as a disease of young people (Goodroad, 2003; Nevedal & Sankar, 2015). This can be partially attributed to Western society's ageist attitudes regarding elder sexuality, which views older adults as being sexually inactive and/or monogamous and therefore not at risk for HIV (Levy-Dweck, 2005; Nevedal & Sankar, 2015). As such, a large focus in education and prevention programs have targeted youth, leaving older adults "virtually invisible" (Wright et al., 1998, p.5). The perception of HIV as a youth centric disease, coupled with the many stereotypes and misconceptions regarding the sexuality of older adults, have resulted in low levels of sexual risk and HIV knowledge among older adults (Beaulaurier et al., 2009; Goodroad, 2003; Jang, 2011; Waysdorf, 2002). Contrastingly, an earlier study by Wright et al. (1998) found that older adults were fairly knowledgeable about HIV/AIDS. However, the authors only described participant's awareness of risks of HIV exposure to be to "some degree" (Wright et al., 1998, p. 14).

Health care providers are also impacted by these stereotypes, which translates into low clinical suspicion of HIV in the older adult population, leading to a low adoption of testing rates and thus, delayed diagnosis and treatment (Ory et al., 1998; Sankar et al., 2011; Waysdorf, 2002; Zelentz & Eosteubm 1998). Cahill and Caladez (2013) have found that, "health care providers tend not to assess older patients for sexual health--- related risks, regardless of sexual orientation and gender. A national study revealed that adults aged 50 years and older at risk for HIV were 80% less likely to be tested for HIV than were younger people" (p. e11). This situation is compounded by the fact that many health care providers may not feel comfortable addressing

sexual issues with older patients (Wooten-Bielski, 1999). Likewise, many older adults may not feel comfortable discussing their sexual history with doctors (Wooten-Bielski, 1999).

### *Sexuality*

Despite the many stereotypes regarding elder sexuality, a large majority of older adults remain sexually active as they age (Cahill & Valadez, 2013; Crisologo et al., 1996; Levy-Dweck, 2005; Nevedal & Sankar, 2015; Szirony, 1999). Due to the lack of information and vulnerabilities in relation to age and gender previously discussed, older adults are potentially at an increased risk of acquiring and transmitting HIV (Cahill & Valadez, 2013; Nevedal & Sankar, 2015). Additionally, erectile dysfunction in males during intercourse can make condom use more difficult (Beaulaurier et al., 2009). Beaulaurier et al. (2009) points out the irony in the use of erectile dysfunction drugs in that it may increase the inclination of older persons to engage in sex, thus increasing chances for transmission. This should be of great concern given that age-related physiological changes appear to make older adults more vulnerable to HIV infection than younger adults (Speer et al., 1999) and that high risk sexual behaviour is a leading cause of transmission in the older adult population (Beaulaurier et al., 2009; Crisologo et al., 1996; Emler & Farkas, 2001). Szirony (1999) has said that, “a risk factor for older adults, as well as many younger adults, is that they often do not view themselves at risk for developing HIV/AIDS” (p.26). Sankar et al. (2011) found that even after an HIV diagnosis, older adults were reluctant to take preventive measures. For example, older adults are more susceptible to HIV because they report inconsistent levels of condom use (Emler et al., 2013; Nevedal & Sankar, 2015; Orchi et al., 2008).

## ***Sexual Orientation***

With roughly half of the American population living with HIV identifying as gay or bisexual men, the need for cultural competency regarding the needs of LGBTQ and two spirit community members is vital (Cahill & Caladez, 2013). Brennan-Ing et al. (2013) illustrate that individuals who identify as LGBTQ often experience unwelcoming environments, staffed by health care providers whom lack basic knowledge about LGBTQ issues and thus, consideration is not given to sexual orientation or an individual's gender identity. In addition, some older, homosexual and bisexual men may not be comfortable speaking about their possible HIV risk with service providers because they, "lived through a period when homosexuality had to be concealed" (Wooten-Bielski, 1999, p. 269). From these findings it is extremely evident that the intersections of age, race/ethnicity, gender and sexual orientation are greatly impacting the rates of transmission, diagnosis and treatment of older adults with HIV.

## **Conclusion:**

Within the literature, there is ample evidence supporting the "greying of the epidemic". It is clear that the advent of HAART has significantly increased the longevity of individuals living with HIV. Many scholars describe a shift that has occurred in the course of the disease itself, describing HIV as a once highly infectious, life threatening disease to a more manageable chronic condition (Brennan et al., 2013; Cahill & Valadez, 2013). However, Beuthin et al. (2015) and Owen and Catalan (2012) caution people from describing HIV/AIDS as a chronic condition because this classification can be misleading. The interactions between HIV, pharmacotherapy,

and aging are complex, presenting many new challenges for older adults and the health care professionals providing care for them.

While it is clear that older adults experience many of the same psychosocial challenges associated with HIV such as stigma, fear of disclosure, depression and social isolation, as their younger counterparts, it has also been identified that aging may exacerbate some of these challenges, thus, making the experience of older PHA's unique from younger PHA's. Similar to the process of aging itself, the experience of living with HIV is formed more by an individual's social, physical, cultural, and economic background than by biological aging (Sankar et al., 2011). Given that HIV tends to disproportionately affect minority groups, experiences of multiple stigmas are common for PHA's. The layers of stigma experienced by PHA's include: HIV stigma, racism, sexism, homophobia, and ableism. Additionally, many older PHA's may experience ageism as well. The intersections of multiple stigmatizing identities are complex and need to be given consideration when interventions regarding; transmission, prevention, treatment and care are created. While there is a growing body of literature on the physical aspects of aging and HIV, more attention needs to be drawn to the psychosocial and sexual health of older individuals living with HIV. Given the ramifications of the "greying of the epidemic", this consideration is necessary internationally.

In order to meet the needs of this population and to prevent more incidences of HIV from occurring in the 50 plus population, ageism needs to be confronted. Ageism combined with HIV stigma continue to contribute to the lack of education, prevention and treatment targeted at the older population (Bhavan et al., 2008; Levy-Dweck, 2005). This stigma and resulting lack of

education can have devastating consequences as it leads to under testing and thus under diagnosing of older adults with HIV. This lack of testing often results in older adults being diagnosed at advanced stages of the disease, making older adults more likely to progress to AIDS than their younger counterparts (Balderson et al., 2013; Ellman et al., 2014). When older adults are diagnosed they may face discrimination by their peers and service providers. This is extremely problematic, given that older adults tend to have smaller informal social networks, thus, they often require additional support in managing and controlling the disease (Brennan Ing et al., 2014; Levy-Dweck, 2005). All of these reasons highlight the importance of research which examines not only the social aspects of HIV and aging with regards to education, prevention and treatment but also research that recognizes the heterogeneity of the aging, HIV positive population.

The demographic trends in Canada show a rapidly increasing aging population and an expanding Aboriginal population, which have both been identified as having an elevated risk of acquiring HIV/AIDS. Although these findings are well known, the lack of research on the social aspects of aging with HIV from a Canadian specific context is concerning (Roger et al., 2013). Even more troubling is that this literature review found no research on the aging Aboriginal, HIV positive population in Canada. There is a need to examine the cultural histories and perspectives of older First Nations, Métis, and Inuit populations aging with HIV and highlight the significant differences between each group and also differences within these group(s). This is particularly relevant for First Nations both on - and off - reserve, as well as rural and urban populations. It is also necessary to interweave gender into lens-based work that acknowledges older Aboriginal women and men and how their experiences with HIV are similar and/or different and how this

will impact future policies and programs. Additionally, upon review of the literature, we know that the successful aging discourse was developed based on Western values and therefore its application to other cultures is questionable (Liang & Luo, 2012). Thus, it is also important to consider what successful aging looks like in the context of aging with HIV from an Indigenous lens. Ultimately, given what we know about the demographic trends in Canada and the confounding intersections of HIV stigma with ageism, sexism, homophobia and race/ethnicity, research specific to the social aspects of aging with HIV from an Indigenous specific focus is of particular importance.

## Chapter Four: Methods

### Objectives

The current project developed as part of a community-academic partnership with the goal of developing a larger exploratory study to examine ways in which Indigenous peoples experience growing older with HIV, and to identify culturally resonate approaches to a holistic care cascade for this population. This project was conceived of from the community through a joint dialogue between members of the Canadian Aboriginal AIDS Network (CAAN) and the research team. CAAN is a national non-governmental organization dedicated to providing, support and advocacy for Indigenous people living with and affected by HIV/AIDS regardless of where they reside. CAAN members have expressed concern about a perceived lack of culturally mediated responses to living with HIV among Indigenous people, health, and social service providers (Renee Masching, personal communication, 2015). Further research is needed to gain a better understanding of the lived experiences of this diverse population so that we can work towards effective, culturally resonate strategies which can help facilitate successful aging amongst older Indigenous peoples living with HIV/AIDS. Ideally, this knowledge can be used to help structure community and primary health services to promote successful aging with HIV in ways that are congruent with Indigenous culturally-defined notions of health and well-being. Knowledge gathered from this thesis project is merely a starting point for a larger project which will be even further grounded in community members concerns about aging with HIV. This project was made possible through the contributions of a Canadian Institute of Health Research (CIHR) planning and dissemination grant. Data collected from this project has been used to guide a subsequent CIHR catalyst grant application on Indigenous peoples, aging and HIV.

Recognizing that the successful aging framework is highly problematic and is based on Western empirical data, it was used as a starting point because it is the dominant conceptual framework in social gerontology (Liang & Luo, 2012). Therefore, it is not without consideration that this discourse was utilized in this project. In order to help move the larger research projects agenda forward, my research intended to explore what successful aging means to, or looks like for Indigenous peoples aging with HIV. Successful aging was not chosen without reflection on its application to Indigenous cultures, rather it was chosen to examine how it is perceived from an Indigenous cultural lens.

Given that the aim of this project was to examine successful aging and by extension, resilience within the aging, positive, Indigenous population and further, to identify enablers which allow this population to age successfully with HIV, a qualitative research design was practical. Resilience is most commonly defined as, “positive adaptation despite adversity” (Fleming & Ledogar, 2008, p.2). More importantly, resiliency provides an approach that encourages research to move beyond problem identification and resolution towards identifying strengths and actualization (Riecken, Scott, & Tanaka, 2006). The use of a qualitative framework supports this project’s exploratory approach of resiliency within this population, allowing for the exploration of individual’s experiences expressed through stories. Stories are descriptions of experiences but most importantly, they shed light on how an individual understands and/or constructs their reality. This methodology is harmonious with Indigenous worldviews which are formulated by oral narratives through representation, connection, storytelling and art (Barton, 2004). This type of approach recognizes the traditional power imbalances in research and works to mitigate such imbalances through mutual respect and cultural safety. However, undertaking a



mainstream qualitative approach which is harmonious with Indigenous epistemologies is not enough. Due to the colonial context that has dominated the Indigenous health research field, it was extremely important that this project avoided the further perpetuation of colonial ideologies through the research process. In order to do so, the inclusion of Indigenous knowledges and decolonizing methodologies was utilized throughout this project.

The generation and application of Indigenous knowledge has been described as participatory, communal, experiential and reflective of localized geography (Martin, 2012). Whereas, western knowledge which is firmly rooted in positivism, “assumes that there is only one reality out there, which can be discovered through scientific procedure” (Martin, 2012, p.25). Martin eloquently explains,

The collective nature of Indigenous knowledge rests on stories derived from practical experience. The oral tradition of storytelling provides the foundation for local knowledge by helping people to connect their own experiences with those from the past. By sharing their personal experiences and learning about the experiences of others through stories, individuals develop wisdom, which is then passed on to the younger generations. (2012, p.34)

Furthermore, a diversity of perspectives and opinions are valued, because it is thought that no one perspective is right or wrong; all views are valued for their unique contributions and are seen as important (Martin, 2012). The valuing of diversity amongst perspectives in Indigenous knowledge starkly contrasts with Western knowledge which fails “to acknowledge the existence of perspectives that might question or contradict some of its fundamental assumptions” (Martin, 2012, p. 24). Decolonizing research methodologies aim to “disrupt the history of exploitation, suspicion, misunderstanding, and prejudice’ of Indigenous peoples in order to develop methodologies and approaches to research that privilege Indigenous knowledges, voices, experiences, reflections and analysis of their social, material, and spiritual conditions” (Smith,

2007, p.116). Absolon (2011) argues for a 're-search methodology', which allows for decolonizing research and the opportunity for Indigenous peoples to re-search, re-write and re-right their own realities and truths, as well as involve the re-emergence and assertion of Indigenous knowledge. Thus, research which draws on Indigenous knowledge is one way to decolonize research. Additionally, Bartlett et al. (2007) cite giving the appropriate credit of Indigenous knowledge to Indigenous peoples as being critical to decolonizing research.

This type of approach to research is fundamental to the project because it enables the research to be grounded in community and informed by Indigenous knowledges and methodologies (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007; Denzin & Lincoln, 2008). Lavallée (2009) believes that by including Indigenous knowledge in research versus the usual reliance on Western knowledge is a way to decolonize the field. Two-eyed seeing represents a framework which embraces the foundations of both Indigenous and Western epistemologies (Martin, 2012; Bartlett, Marshall, M., & Marshall, A., 2012) and thus, provides an example of a decolonizing methodology. Jackson, Debassige, Masching and Whitebird (2014) discuss the importance of drawing on the strengths of each perspective and integrating them to approach social phenomena. Therefore, throughout this project, principles of two-eyed seeing were used to guide this research, in order to avoid the traditional vertical ordering of knowledge, where Western knowledge is privileged and Indigenous knowledge is undermined. In order to integrate a two-eyed seeing framework, I have drawn on the knowledge of the research team, research participants including the Elders involved in this project, and the Indigenous members of my thesis committee.

In addition to the successful aging framework outlined above, constructionism will also inform my research. Methodologically, constructionism adopts qualitative approaches which focus on meaning; and the methods preferred are usually interviews and unstructured observations (David & Sutton, 2011). This epistemological paradigm was employed because it is an approach that focuses on the cultural context in which people construct knowledge and language (Stewart, 2008). This theoretical tradition is in line with Indigenous perspectives which focus on holism and respect for individuals. Another reason this research paradigm has been chosen is because of its relevance to cultural phenomena. First Nations scholar, Charlotte Loppie (2007) points out the parallels between Western constructivist and Indigenous paradigms, given that they both acknowledge that reality is a product of multiple human constructions, created from the perceptions and actions of individuals and communities. Cultural competence is an extremely important aspect of this research, so the recognition of the importance of culture on constructing meaning is fundamental to this project.

Narrative inquiry as a guiding framework coincides well with the theoretical tradition of constructionism. Both, method and paradigm complement one another and they are both congruent with an Indigenous worldview. Both recognize research as a subjective process based on the co-construction between the interviewer and the participant (Wells, 2011). Constructionism strives for thoughtful and precise descriptions (interpretations) of social practices to understand how participants experience and explain their own world and a composite inquiry allows for this. Narrative inquiry is premised on the belief that individuals can make sense of the world around them by telling stories, and narrative analysis examines participant's stories which emerge from qualitative data collection (Stewart, 2008). Barton (2004) describes

narrative inquiry as a "relational methodology when used in an Indigenous context, where epistemological implications of Native ways of knowing for academic interest, demonstrate how Indigenous epistemology can influence knowledge and practice in research" (p. 5 19).

Keeping with attempts to decolonize this project, a narrative inquiry framework was initially adopted as a way to explore individual's experiences expressed through stories, because as previously discussed, this framework has been recognized as being congruent with Indigenous epistemologies. Furthermore, through the sharing of views, narrative inquiry encourages experimentation of creating new ways of knowing by intersecting the experience of a researcher with the experiences of participants (Barton, 2004). Barton describes narrative inquiry, "as a methodology congruent with Aboriginal epistemology, narrative inquiry could be about witnessing an insurgent effort by Aboriginal people to reclaim confidence in their identities, regain a political voice, and heal from colonial injustices of the past, it is about a whole life" (2004, p.520). Barton (2004) suggests narrating is a way to discover deeper historical, cognitive and ethical dimensions that come from individual's lives, including how they are experienced and lived out. However, the work of Jackson, Debassige, Masching & Whitebird (2014) encouraged the use of a narrative inquiry framework as a mere starting point - intertwining it with Indigenous knowledge to create a composite narrative. Jackson et al. (2014) state that, "composite narratives, for us, are meant to be interactive and attentive to the audience, maintain oral tradition, and draw on ancient Indigenous tribal wisdom through traditional stories" (p. 136). Ultimately, a composite narrative, similar to other forms of storytelling is decolonizing due to its focus on remembering, visioning and creating equilibrium (Jackson et al., 2014).

In order to meet the objectives of this project, three main methods of data collection were utilized. First, a literature review was conducted, which looked at peer-reviewed, journal articles on aging and HIV/AIDS within the global Indigenous population. The second method consisted of focus groups which were adapted to sharing circles and were held with women, men and service providers. And lastly, semi structured interviews were conducted with participants who were either unable to attend the sharing circles, or felt more comfortable in a one on one interview setting. Each method of data collection will be explained in further detail, below.

As previously discussed, a rapid literature review was conducted on the social aspects of aging in relation to Indigenous peoples with HIV/AIDS. The search was conducted between May and July of 2015 to identify relevant academic journal articles. A rapid literature review uses accelerated or streamlined methods in comparison to traditional systematic reviews (Ganann, Ciliska, & Thomas 2010). Sociological Abstracts, PsycINFO, AgeLine and Scholars Portal, were the electronic databases that were used for this search. These electronic databases were selected based on consultation with a McMaster University librarian. The following key terms were searched in various combinations: Aboriginal\*, Aborigine\*, Indigenous, native\*, "first nation\*", "first-nation\*", "1st nation\*", "1st-nation\*", Indian\*, Amerindian\*, tribal, autochtone\*, Amerindien\*, Aborigene, Indigene\*, and HIV, HIV positive, HIV-positive, HIV/AIDS, AIDS, HIV and AIDS, Living with HIV, Living with AIDS, Living with HIV/AIDS, HIV affected, and aging, aged, longevity, older adult\*, senior, young old. The terms which were used to search for literature specific to Indigenous peoples were chosen to be inclusive of the global Indigenous population. These search terms were selected in consultation with thesis committee members Randy Jackson and Dr. Chelsea Gabel. The decision to expand the search to be inclusive of the

global Indigenous population rather than a Canadian specific or North American Indigenous population was in response to the paucity of literature on the social aspects of aging with HIV/AIDS in general (Roger et al, 2013), and the apparent absence of literature in this area specific to Indigenous peoples. Shortly after the search was expanded to be representative of the global Indigenous population it was evident that no such literature existed, be it on the North American Indigenous population or on the global Indigenous population. Therefore, a search was conducted on the social aspects of aging with HIV/AIDS.

The following questions were used as inclusion criteria to screen the studies yielded from the above searches: (1) Does the article include a focus on the social aspects of aging with HIV/AIDS? (2) Does some component or this entire article focus on the 50+ population living with HIV? (3) Does this article address either older adults living long term with HIV and/or those diagnosed over the age of 50? (4) Was the data in this article collected  $\geq 1996$  (post introduction of HAART)? (5) Does the article include a focus on Indigenous peoples or include Indigenous participants? Journal articles were excluded if they did not meet inclusion criteria 1-4. A note was made if the article met the 5<sup>th</sup> inclusion criterion.

Searching the key terms listed above on Scholar's Portal yielded 5986 results, AgeLine on Ebsco yielded 763 results, and Sociological and PsycINFO Abstracts on Proquest yielded 668 results. In total 7417 abstracts were read through. Out of these 7417 articles only 200 were identified as meeting the inclusion criteria listed above. The abstracts of these 200 articles were compiled into a word document and sent to research team member and thesis committee member, Randy Jackson, and Dr. Chelsea Gabel, for further consideration of whether or not the

articles should be included. Upon further investigation 64 out of the 200 articles were found to not meet all of the inclusion criteria. We also came to a collective decision to exclude articles which focused solely on service provision, service utilization and prevention. The remaining 136 articles were read using an open analytic approach to explore the content of the literature and to draw themes from the text. During this phase an additional 34 articles were flagged as not meeting some of the inclusion criteria and/or were too heavily focused on service provision, service utilization and/or prevention. Once all members agreed, these 34 articles were excluded, resulting in a total of 102 articles included in the literature review.

Throughout the open analytic process used to explore the literature, several common themes emerged. These themes and key passages were analyzed in more detail to come up with larger conceptual categories which were found to emerge from the text. These categories were actively reviewed and revised by myself, Chelsea Gabel and Randy Jackson, using an inductive and iterative process and passages that contradicted the themes were sought out. Each of these themes are detailed in the literature review section below.

### **Community Based Participatory Research (CBPR)**

In order to undertake this research, a CBPR approach was developed jointly between the research team and members of CAAN. The research team is made up of myself, Randy Jackson, Renee Mashing and Dr. Alexandra King. In addition to being a member of my thesis committee, Randy Jackson is an Anishinabek scholar originally from Kettle and Stony Point Nation, and a PhD and pre-doctoral candidate in the School of Social Work and the Department of Health,

Aging and Society at McMaster University. Randy has been involved in a number of research projects that engage community and that incorporate Indigenous values and perspectives (e.g., HIV testing among Aboriginal youth; HIV stigma and use of health services; cultural competence in HIV-related health services, etc.). Randy brings extensive background and experience in CBR utilizing decolonizing and Indigenous methodologies among Indigenous populations in Canada. Renee Masching is a First Nations woman, registered with the community of Six Nations of the Grand River. Additionally, she is the Director of Research and Policy with CAAN and she has extensive experience within the Indigenous HIV and AIDS community. Dr. Alexandra King is a member of Nipissing First Nation, and she is an Internist specializing in HIV/HCV care. She is also pursuing a PhD focused on improving the HIV/HCV care cascade engagement of Indigenous women with criminal justice system involvement. Thus, the research team is inclusive of academic and community stakeholders.

A CBPR research design is central to an Indigenous methodological approach. This is because a CBPR project with Indigenous peoples should involve full participation of the community in shaping the research question, design, methods, analysis, interpretation and dissemination (Lavallée, 2009). The Tri-Council Policy Statement 2 (TCPS 2) defines participatory research as, “a systematic inquiry that includes the active involvement of those who are the subject of the research” (CIHR, 2010, p. 124). In accordance with the TCPS 2 requirements of CBPR, CAAN has significant control over the development and facilitation of the project. The TCPS 2 describes this type of research as action-oriented, highlighting the fact that those involved in the research have the opportunity to collectively define the project, collect and analyze the data, and have a say on the results of the project (CIHR, 2010). Based on this



description, it can be said that this research is action-oriented, since CAAN members largely shaped the conception of this project and remained involved throughout the data collection, analysis and dissemination of findings. Joint engagement between myself, members of the research team and members of CAAN was and remains to be fundamental to this project given the history of research involving Indigenous peoples in Canada.

In accordance with Lavellée's suggestion, this research respects "the core values, beliefs, and healing practices of the Indigenous community [...] throughout the research process" (2009, p. 23). This can be demonstrated through the following measures which were undertaken throughout the research process, 1) focus groups were adapted to sharing circles, 2) Elders were included in the data collection, 3) each sharing circle began with a prayer led by the Elder and in some cases the prayer was done in conjunction with a smudging ceremony, 3) tobacco was offered to participants at the start of each sharing circle and interview, 4) a two eyed seeing methodology which embraces Indigenous knowledge as well as Western knowledge was utilized.

To fully ground this project in Indigenous Canada-wide community concerns, the sharing circles described below were undertaken during CAAN's Fifth Bi-Annual Wise Practices Aboriginal CBR Conference, which was held in Vancouver, British Columbia in July, 2015. Conference delegates include:

Aboriginal Persons with HIV/AIDS, community workers, government representatives, students, researchers and academics, health care providers, and community members all connected through a shared commitment to the response to HIV and AIDS in Aboriginal and Indigenous communities (CAAN, 2015).

The goal of Wise Practices is to not only showcase recent research which has been conducted but also offer skills-building to community members about research. It also provides an opportunity for researchers to engage in community consultation about future research plans and goals.

During the Wise Practices conference, a caucus is held where members have the opportunity to discuss concerns and provide recommendations related to their experiences with HIV/AIDS.

Over the course of the Wise Practices conference, members of the research team had the opportunity to engage with members of the APHA (Aboriginal peoples with HIV/AIDS) community, in the form of sharing circles, interviews and a work shop which was open to conference delegates, led by myself, Randy Jackson and Dr. Alexandra King.

To reiterate, the purpose of these sharing circles and interviews were two-fold. First, the goal was to collect data specific to resiliency and successful aging within this population, to be analyzed for this thesis project. And, second, the goal was to collect some data about how HIV and AIDS affects Indigenous peoples later in life, in order to narrow the research focus for a larger operating grant application, which will be even further grounded in the concerns of this community.

## **Ethics**

In addition to the ethics requirements set out by the McMaster Research Ethics Board (MREB), recommendations highlighted within Chapter 9 of the Tri Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) entitled “Research Involving the First Nations, Inuit and Métis Peoples of Canada,” were also followed throughout this research project

(CIHR, 2010). Based on the definitions provided within Chapter 9 of the TCPS 2, CAAN is recognized as an “organizational community”, which means that the same ethical protocols for engaging with an Aboriginal community must be followed (CIHR, 2010). Thus, prior to data collection, the project’s methods were submitted for approval to the McMaster Research Ethics Board (MREB). Additionally, a Principles for Research Collaboration (PRC) between research team members and CAAN was created (see Appendix A). Within this document it is noted that CAAN will participate as a member of the research team through Renee Mashing’s leadership. Furthermore, this research project recognizes and supports the use of OCAP™ principles: Ownership, Control, Access and Possession. Given the unique circumstances of this project, a formal relationship was already established between CAAN and the other members of the research team before I joined the project. Therefore, I did not need to seek approval from CAAN to go ahead with this project. The project was however approved by the MREB after minor revisions were made in April, 2015.

## **Sharing Circles**

One of the research techniques this project utilized was the focus group. One of the main advantages to focus groups is its ability to redress the traditional power imbalances between the research participants and the researcher, since collectively a group may be able to wield more control over the research than a single participant (Saks & Allsop, 2007). Perhaps the main methodological advantage of a focus group is that it provides an opportunity for the researcher to observe interactions between participants which allows access to more ‘naturalistic’ talk about the topic (Saks & Allsop, 2007). Furthermore, Saks and Allsop (2007) state that focus groups are

ideal when research questions address sensitive issues because a group setting tends to be a more supportive environment for participants. While focus groups would be an appropriate method for this research, this traditional, Western method was used as a starting point for data collection. Reflecting further attempts to utilize, Indigenous, decolonizing methodologies, focus groups were adapted to sharing circles. Adopting a sharing circle format is meant to highlight the continuing and central importance of oral tradition and storytelling for Indigenous people and also provides a cultural signal to Aboriginal participants that the process is premised on egalitarian, supportive, non-confrontational values meant to solicit collective identification of problems and solutions (Rothe, Ozegovic, & Carroll, 2009). Lavallee (2009) describes how sharing circles although similar to focus groups, differ because of the sacred meaning they hold in many Indigenous cultures, more specifically First Nations, due to their ability to facilitate growth and transformation bases for those who participate. Furthermore, “sharing circles use a healing method in which all participants (including the facilitator) are viewed as equal and information, spirituality, and emotionality are shared, a method that is familiar and comforting for some Aboriginal participants in Canada who have this knowledge of this practice” (Lavallee, 2009, p.28).

Sharing circles were moderated by myself and Randy Jackson and in an effort to gain trust and reduce any potential power imbalances, an Elder was involved in this process. Additionally, sharing circles began with the researchers offering participants tobacco to thank them for their participation and to symbolize their efforts to do the research ‘in a good way’. Next participants were each given a Letter of Information (LOI) and Consent Form to review and sign if they chose to proceed with the research. After a few minutes, we reviewed the LOI and

consent forms collectively, to clarify any questions or concerns participants had. After this, participants were asked to sign and submit their forms to myself. As participants submitted their signed consent forms they were handed their financial compensation (\$25) to illustrate that their compensation would not be affected if they chose to withdraw from the sharing circle at any point. Upon the exchange of consent forms and financial compensation, the sharing circle was turned over to the Elder.

Three different Elders were involved in the four sharing circles held. For our first sharing circle with women, we had a female Elder from Squamish First Nation, in British Columbia. For our second sharing circle with women we had another female Elder from Saskatchewan. And for our sharing circle with men and service providers we had a well-known male Elder, Cliff Thomas from Ontario. All four Elders led the sharing circle with a prayer and offered their support to participants should they need it during and after the sharing circle. The male Elder, Cliff, also performed a smudging ceremony prior to the start of the data collection. In our first sharing circle with women since there were only two participants, participants spoke openly, answering which ever questions they chose to and often responding to each other's answers. However, since our next three sharing circles were significantly larger (SC2 n=4, SC3 n=16 and SC4 n=8) the female Elder suggested the use of a rock and the male Elder suggested the use of his eagle feather to be used in place of a traditional 'talking stick', where no one spoke unless they held the rock/eagles feather. Furthermore, the Elders explained that the rock and/or eagles feather should be passed around the circle going counter clockwise, so everyone had the chance to answer each question. Not only did this method add to the cultural significance of the sharing

circle, it also provided an equal opportunity for each participant to speak, ensuring that everyone's voices were heard.

Following the Elder's prayers, I began by asking the questions we had previously decided upon. These questions as well as various prompts were laid out on our sharing circle guide (see Appendix B) which I followed to varying degrees throughout each of the four circles. Based on the variations in size of the circles and the time constraint (2 hours), the same amount of questions was not asked in each group. However, in planning for the possibility that this situation may occur, the research team prioritized questions into two categories: primary questions and secondary questions. The primary questions were asked in all of the sharing circles and in some cases secondary questions were asked as well.

## **Interviews**

Over the course of this project, four, semi structured, open ended interviews were conducted by myself. Three interviews were conducted throughout the course of the Wise Practices conference and the final interview was conducted during the week after the conference over Skype. While we had not planned on utilizing interviews as a research method, we were approached by a few participants who expressed a keen interest in participating in the research project, but were not able to attend the planned sharing circle day/times or were not comfortable in doing so. The research team came to a collective decision to accommodate these requests. Methodologically, interviews are complimentary to a composite inquiry which is also congruent with the theoretical tradition, constructionism.

A semi structured, open-ended interview is one in which the interviewer asks specific questions in a prescribed order (Wells, 2011). Since the interviews were not pre-planned, I followed the sharing circle guide (see Appendix B). Although the sharing circle guide was the main data collection instrument, I was not concerned with following it to a tee, instead I allowed for the interview to progress naturally. Although I had no prior relationship with the interviewees, I felt that my connection to the research team who were all well known within the CAAN community helped gain instant trust with the interviewees. This was evident based on participant's ease in discussing sensitive information with me. Prompts and probes from the sharing circle guide were used at times to elicit additional information about a core question (David & Sutton, 2011). While participants were sharing their stories I engaged in the process of "active listening" and posed follow up questions in a way that invited the interviewee to become more engaged in the narratives they were sharing (Wells, 2011).

All circles and interviews were audio recorded and transcribed verbatim. A Dropbox folder was created as a secure online space where team members could review audio recordings and transcripts from the sharing circles and interviews, as well as findings from the literature review. Team members were encouraged to share emerging thoughts and perspectives via Dropbox, regular email correspondence and the occasional teleconference in order to work towards integrating sharing circle and interview findings with findings from the literature review.

## Sample

This project utilized a purposive, non-probability sampling method. In purposeful sampling, sources of information, in this case, participants are selected because they are expected to produce in depth data which will contribute to the achievement of the study's aim (Wells, 2011). Purposeful sampling tends to yield better data and it is most practical due to research restrictions such as time and finances. The choice to only recruit Wise Practices conference delegates was thus a purposeful sampling method. Given that all of the participants in our study (with the exception of the sharing circle with service providers) were conference delegates, this meant that they were all open about their status at least within the CAAN community. Furthermore, while the conference took place in Vancouver, British Columbia, CAAN is a national organization so conference delegates and thus, participants represent a diverse sample of Aboriginal peoples from all across Canada. This again, was purposeful, because it provided an opportunity to sample participants from all across the country in one setting. The sample included First Nations, Inuit and Métis participants from: Northwest Territories, Yukon, British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, and Nova Scotia. While the sample included First Nations, Inuit and Métis participants from two territories and seven provinces it is important to note that the majority of participants identified as First Nations and were from either British Columbia or Ontario. However, this can be considered representative of the Indigenous population in Canada, given that, "nearly 61% of the aboriginal population identified themselves as First Nations (60.8%), 32.3% identified as Métis and 4.2% as Inuit" (PHAC, 2014). Thus, these findings may still be generalizable to the wider Indigenous Canadian experience.



## **Recruitment**

Recruitment did not take place prior to the Wise Practices CBR conference. Recruitment was only conducted during the week of Wise Practices events (July 13-18). The conference took place on the second floor of the Marriott Pinnacle Downtown Hotel in Vancouver, therefore recruitment posters (see Appendix C) were placed all around the second floor, including at the entrances and exits of each meeting room. Additionally, announcements were made about the research during the opening and closing remarks of each day. Recruitment flyers were also placed in conference delegate's registration packages which were received upon arrival to the conference. Lastly, a recruitment poster was included in the printed agenda which was also included in each individual's registration package.

We were looking to recruit participants for three separate sharing circles. One with Indigenous women who were HIV positive and over the age of 50, another with Indigenous men who were HIV positive and over the age of 50, and a third circle with service providers who provide care, treatment and/or support services for APHA's. Our aim was to recruit 6-8 participants for each of the three sharing circles (n= 18 - 24). Recruitment criteria was simply based on the following: 1) Aboriginal identity, 2) HIV positive status, and 3) age 50 and over. However, none of the three criterion listed above were necessary for the sharing circle with service providers. For the sharing circle with service providers, the only criterion was that participants provided care for Indigenous persons aging with HIV/AIDS. There was no definition provided for what was meant by service provision and therefore participants fell into two groups: 1) formal service providers and 2) informal service providers. Participants who were considered

to be formal service providers were employed by various AIDS Service Organization (ASOs). Whereas, informal service providers were not employed by ASOs, providing unpaid care for family, friends and/or neighbour's with HIV/AIDS.

## **Participants**

While our aim was for 18 to 24 participants, a total of 34 participants were involved in this study. We were on target for our sharing circle with women (n = 6). However, this was actually spread out over two sharing circles because our first sharing circle only had two women participate. The first sharing circle was held on the evening of the 14<sup>th</sup> when there were other events being held which could possibly be attributed to the low turnout. The following day several women approached members of the research team expressing interest in participating in the study. Because we did not meet our target for the first circle we agreed to hold a second circle on the evening of the 15<sup>th</sup>. For this second circle with women four participated. In contrast to the rather low turnout amongst women, 16 men participated in the sharing circle which was held on the morning of the 16<sup>th</sup>. Keeping in line with the fluid nature of the project, and the fact that we had the resources to accommodate all of the men, we decided to include all 16 men in the sharing circle. The final sharing circle was held with service providers on the evening of the 17<sup>th</sup>, with eight participants (seven women, one man).

Three additional interviews were held with conference delegates over the course of the week, two of which were with men and one with a woman. Lastly, in the week following the conference one final interview was held over skype with a woman who was also in attendance at

the conference, but was unable to meet over the course of the week. Out of the 34 participants we spoke to, 19 were men and 15 were women. However, it is important to note that 7 out of the 15 women were service providers, and thus, were not living with HIV/AIDS. Therefore, we only had 8 female participants who are living with HIV in comparison to the 18 male participants who are living with HIV.

It is also important to note that not all of our participants were over the age of 50. Though this was initially required as one of the inclusion criterion's we decided to allow individuals under the age of 50 to participate for a few reasons. First, for our sharing circle with women, both of the women who showed up to participate were under the age of 50, and given that they were the only ones to show up we did not want to turn them away because we were unsure if we would have another opportunity to talk to other older women. For our second sharing circle with women, again, individuals under the age of 50 wanted to participate and we did not think it was fair to exclude these women after including younger women the previous day. Similarly, for the sharing circle with men, individuals under the age of 50 expressed a desire to participate and to keep things fair we included them. Additionally, all of the individuals under the age of 50 made the case that they too were "aging" with HIV and furthermore, they wanted the opportunity to learn from their peers about how to "age successfully" with HIV/AIDS. Ultimately, we did not feel it was necessary to turn individuals away, denying them the opportunity to learn from their peers because they did not meet the age requirement.

This flexible, nonlinear approach to the research is characteristic of Indigenous decolonizing methodologies. Perhaps in a strictly traditional, Western academic approach, this

flexibility would be frowned upon. Even further, it may be viewed as a methodological weakness. But given that Indigenous knowledge is fluid and experiential, this flexible approach to the research offered a way to respect and honor cultural protocols and knowledge. Furthermore, given that this type of approach is about recognizing the traditional power imbalances which exist within research and working to eradicate such imbalances, the research team thought turning people away would be counter intuitive to this approach. In order to remain true to our intentions of conducting a decolonizing project, we thought it was important to allow those who wanted to have a voice in our project, to have a voice.

Additionally, as a result of the literature review conducted prior to data collection, the research team was aware of the criticisms Robinson et al. (2008) and Sankar (2011) had of using chronological age as a way to categorize individuals with HIV, rather than on the length of time the individuals have been living with HIV. Being aware of the weaknesses of this approach, allowed the team to make a last minute, informed decision, to include individuals under the age of 50.

## **Limitations**

The current study has some limitations. The first being our sample included a disproportionate number of men. Additionally, the women in this study were younger and more educated than the men. Furthermore, there is some missing demographic information such as age, geographic location where the individual resides and how the participant identifies (First Nations, Inuit, Métis or other). The sample consisted mainly of First Nations and Métis

individuals, with only two participants identifying as Inuit. So while the successful aging model we are proposing is to be an Indigenous specific model, the voices of Inuit peoples may be hidden. However, this may be reflective of the fact that the Inuit make up the smallest segment of the Aboriginal population (4.2%) whereas nearly 61% of the Aboriginal population identify as First Nations (60.8%) and 32.3% identify as Métis (PHAC, 2014). And, “of the 888 aboriginal AIDS cases reported for the period 1979 to 2012, 678 (76.4%) were identified as being First nations people, 60 (6.8%) as Métis, and 23 (2.6%) as Inuit” (PHAC, 2014, p.15). The recruitment strategy may also be viewed as a limitation. Given that participants were all attending a CAAN Wise Practices IV event this means that participants were all open about their positive status and well connected to resources and members of this national Aboriginal community. Therefore, it could be precluded that participants are likely more well-adjusted and coping better than the average Indigenous person with HIV. However, this study is not interested in producing generalizable findings about what successful aging means to ALL Indigenous peoples with HIV, rather it is about creating a successful aging framework that is culturally resonate and community specific, that other Indigenous peoples with and without HIV could adopt to aid them in their journey to age successfully. Despite these limitations, data provided from this study can help advance the aging and HIV literature and the successful aging discourse, and most importantly it can do so in an Indigenous culturally resonate way.

## Chapter Five: Findings

Although traditional models of successful aging require an absence of disease and disability, more holistic, multidimensional models have emerged. The results of our research support emerging models of successful aging which emphasize social cohesion, optimism, spirituality and resilience. Despite the fact that participants in this study are living with a chronic, potentially life threatening disease as well as a number of other comorbidities, individuals considered themselves to be successfully aging. For example, when participants were asked what successful aging means to them, not one individual responded with the absence of disease and/or disability. In fact, when participants spoke about the importance of maintaining good physical health in order to achieve successful aging, they spoke about the importance of a well-rounded diet, the importance of physical exercise, using alcohol and drugs in moderation, getting enough sleep and adhering to their medications. Completely absent from discussions on physical health in relation to aging successfully, was participant's HIV positive status. What emerged as being far more significant to individual's abilities to age successfully was their spiritual, emotional, mental and social health and wellness.

It is also important to note that traditional models of successful aging as well as some of the more multidimensional models tend to dichotomize older adults into two groups of people: those that age successfully versus those that do not. This dichotomy is problematic for a number of reasons. First and foremost, there is no universal definition of successful aging so how do you characterize some individuals as successful and others as unsuccessful? Second, success is value laden and culturally specific. Success as a Western concept may differ significantly from an

Indigenous concept, so how does one account for epistemological differences in measurements? Third, culture aside, success is extremely subjective, and thus should not be measured objectively. Fourth, labelling some individuals as successful agers and others as unsuccessful agers creates an ‘othering’ effect. Fifth, in our increasingly neo-liberalist society, the labelling of individuals as unsuccessful can imply blame and shift responsibility from social institutions such as the health care system to the individual. Ultimately, dichotomizing older adults into successful and unsuccessful agers is harmful, especially when success is being measured by traditional models which require the absence of disease and disability, as these are almost unattainable measures for the aging population. Scholars have argued that this traditional model of successful aging is only attainable for older adults who have benefited from cumulative advantages throughout their life course. Consequently, the idea of successful aging may result in harm to those who have experienced cumulative disadvantages over their life time, which has resulted in being labeled as unsuccessful agers. Furthermore, those who would be harmed the most by this notion of successful aging would likely be those who are already marginalized, such as older Indigenous peoples (Braun, Browne, Ka‘opua, Kim, & Mokuau, 2013).

From an Indigenous perspective, this approach to successful aging is too linear and therefore, an inadequate model for depicting the lived experiences of Indigenous peoples aging with HIV. Similar, to Fleming and Ledogar’s (2008) criticism of resilience from an Indigenous perspective, successful aging should be approached from a relational rather than a linear world view. According to Long and Nelson (1999) a relational world view encompasses “the context, the mental, the physical and the spiritual” (as cited in Fleming & Ledogar, 2008, p. 8). In order to do this, this study sought to examine what successful aging means to Indigenous peoples who are

living with HIV, rather than trying to quantify successful agers within this population. By doing so, a far more inclusive and attainable picture of successful aging emerged. Participants did not view successful aging as a quantifiable dichotomy where they could only be considered as successful or unsuccessful. Rather, the idea of successful aging that participants elucidated paints a far more holistic picture. What emerged was a fluid, interconnected model of successful aging in which five dimensions of health materialized as being important to a participant's understanding of successful aging.

### *Spiritual*

While traditional models of successful aging did not recognize the importance of spirituality in an older adult's life, a growing number of scholars are advocating for its inclusion (Martinson & Berridge, 2014; Crowther, Parker, Achenbaum, Larimore, & Koenig, 2002). Regardless of age, religion and spirituality have been associated with better health outcomes. For many, religion and spirituality provide important coping mechanisms, buffering individuals from stressors such as HIV stigma. More specifically, within the gerontological and chronic disease literature, the biopsychosocial benefits of spirituality and religion have been adequately demonstrated and a handful of studies have even identified this link for adults living with HIV (Brennan, 2008; Vance et al., 2011). Simoni and Ortiz (2003) found spirituality to be a protective factor against depression for HIV positive older men of ethnic/racial minorities (as cited in Brennan, 2008). For Indigenous peoples, Fleming and Ledogar (2008) describe spirituality as a social dimension of resilience and as a resource for "navigating life" and for transcendence. Additionally, a study conducted by Lewis (2011)



with Alaska Native Elder's recognized spirituality as being one of the four elements necessary to achieve Eldership/successful aging.

I find, I need, as I age, I need balance, holding this eagle's feather and smudging during ceremonies and just being with my brothers and sisters (Male, First Nations, British Columbia, 55).

I physically feel that I went through the infant, went through the youth, went through the adult and now I am starting that Elder stage and there is, there is a vision and a clarity and a wisdom that's in that stage if I am practicing my mindfulness and paying attention to that. So I try to stay focused on what I am getting, right, the gifts I am getting and I am not being preoccupied on what I think I am losing (Male, Métis, Ontario, 57).

That is [sweat lodge] the only way I know to take the stress off and all that stuff that I gather up in society and I can leave that in the lodge when I walk out and let the ancestors take care of it... When I'm sick, I go to Lakota lodge and it works, I think that's it, for me, its tradition, it's tradition is the only reason I am here today and able to keep going and go to school and studying with a brain that's been HIV for 28 years, and then everything else on top of that, you know? (Male, Jackatar, Nova Scotia, 57).

Sometimes I can get to that ugly part of the brain where you can have fear and you can let that over run but that's really when I pick up the medicines and I really think about the helpers that I have around me, even saying my name, to really ground me, to pull me back. That's powerful, that's more powerful than any ART, or any codeine or morphine, or those types of things (Female, First Nations, Saskatchewan, 32).

Well as a Métis woman, I am only now learning about that. So for me it means learning, I'm a perpetual learner. It means discovering both sides and learning how to walk in two worlds, because I grew up in a more westernized family from parents who didn't know any better because they weren't taught anything different. So for me it's about learning and growing spiritual (Female, Métis, unknown, 40).

I practice my spirituality and I do a lot of healing work on myself. And I also have traditional healers that I go to, and mostly at events like this. And they are made available to us. But outside of this community here, they are non-existent, or they are not cost efficient for us. So, it's um - it's, once a year I get to join a group with traditional people, and it's something that I find, very, very healing, in a lot of ways (Female, First Nations, British Columbia, 63).

This study supports these findings and recognizes spirituality as being one of the five dimensions of health and wellness necessary for Indigenous peoples living with HIV to age successfully. The importance of spirituality is demonstrated throughout participant's quotes

which highlight the role that spirituality has played in their abilities to cope with aging with HIV. An individual's spirituality typically manifested in one of two ways. For some, their spirituality was innately connected to their Indigeneity, either through learning about their culture and traditions for the first time, or strengthening and/or reconnecting with their cultural and spiritual traditions. Whereas for others, their spirituality was independent of their Indigeneity. Regardless of the foundation of an individual's spirituality, the positive impact that spirituality played in these individual's lives was palpable. Similar to Lewis' (2011) study the participants did not explicitly state that they believed there was a connection between their spirituality and better health outcomes, rather they described how it contributed to their sense of balance, which is an important notion in Indigenous health and wellness. Furthermore, participants did continuously recognize spirituality as a central component to successful aging. RCAP (1996) describes Indigenous spirituality as something vastly different than a system of beliefs that can be defined like a religion, instead, it describes a way of life where individuals acknowledge that every element of life is infused with spirit, and all human

### ***Emotional Wellness***

Participants commonly related to one another based on similar hardships they experienced over the course of their lives. While this seemed to foster an open and supportive environment for participants to share very personal and at times, traumatic experiences, it also clearly highlighted the emphasis that participants placed on the importance of overcoming adversities. Participants demonstrated the importance of overcoming challenges to nurture their emotional wellness. A prevalent theme throughout discussions on emotional wellness was the importance of self-love. Discussions about self-love illustrated a process that many individuals

have undertaken or are currently undertaking, as self-love is recognized as being instrumental to one's emotional wellness. Similar to the idea of self-love was the notion of acceptance that also emerged as foundational to emotional wellness and was thus also a prerequisite to successful aging. In another study that looked at the strengths within the aging, HIV positive population, participants identified self-acceptance as a way to overcome the challenges of aging with such a stigmatizing disease (Emlet, Tozay & Raveis, 2011). In this study, the notion of acceptance was specific to one's identity not only as an Indigenous person but also as an HIV positive person, as many participants have experienced discrimination at some point based on their Indigeneity and HIV status.

Successful aging for me is that I will be, confident and my self-esteem remains intact and um, self-acceptance, which is very hard to do, especially when your hair is greying and you have to dye it all the time, and your wrinkles are starting to come from everywhere and when you are not used to it and the process is like, okay is it from the HIV medications, you know the lipodystrophy thing or is it from aging? ...And I feel that sometimes it's very hard for me to even want to be an Aboriginal woman, because of, regardless of the HIV, there is a lot of stigma against, it seems like we are less then and are treated less then. And we need to, well I worked so hard to change that within myself and not rely on others, other people's opinions and I'm just happy being me (Female, First Nations, British Columbia, 63).

My sister asked me if I was okay, I said, yeah, I'm okay. But she knew something was wrong so I said okay, I'll tell you, I'm HIV positive and Hep C positive, and she said, "it's okay my brother, I still love you". So I started - and I went on the meds and I started getting better, healthier and I started accepting it and I started participating in programs and the healing circle, where other HIV positive people go (Male, First Nations, Manitoba, 51).

But once I embrace myself and I totally forget about HIV, I don't even know I have HIV anymore. I am just a person who wake up in the morning and go out and live life and other people just don't do that, so you have to, accept, everything before you can embrace and spread the joy to other people (Male, Métis, Newfoundland, 52).

I have realized that I do have a lot of gratitude, this may sound funny to some, but I am grateful to have HIV because I can accept it and also it has made me learn a lot more about my condition, my medications, about all sorts of things, so it has really made me, it has really helped me with that. And also part of it is looking back and realizing what I did was a path in the past and a lot of fun and it was also, not, I'm not a 25-year-old anymore, my body is

different, my liver - I turned 53 a few weeks ago, but sometimes I still feel like I am 19 going on 25, and there are sometimes when I just get knocked on my ass and I have to take a day and a half off just not do anything (Male, Native American, British Columbia, 53).

I can honestly say by my heart that I thank the creator for my illness, by my heart. That's not what I set out in life to do was to get infected by HIV but I say this because it changed my life around and it unfortunately had I listened to other people before maybe my life wouldn't have taken the turn it did but needless to say, it did. but, rather than bellyache over it, I thank creator for it because it changed my life around and made me a better person and now I enjoy things rather than take things for granted (Female, First Nations, Saskatchewan, 46).

I have had HIV for 22 years and if I could go back and do it again, I wouldn't. I wouldn't change the life I had for the life I have now, friendship in this room, family and everything, wow, it's awesome, and I love it. Thank you, miigwetch (Male, First Nations, Ontario, 43).

In addition to the importance of achieving self-love and acceptance, especially in light of having multiple stigmatizing identities, participants recognized the significance of gaining confidence and having a strong self-esteem as major contributors to their emotional wellness. While acceptance is recognized as being a common coping mechanism and stigma management strategy within the HIV and aging literature (Foster & Gaskins, 2009, Emler, Tozay & Raveis, 2011), a sub-dialogue based on acceptance developed in this study demonstrating a shift from acceptance to gratitude. Poindexter's (2004) study on six older adults with HIV found that gratitude for life and love was common, however, absent from this discussion was individual's gratitude for the disease itself. Whereas this study found that participants were not only grateful for one's life but also for acquiring HIV. For some participants their HIV diagnosis was a catalyst for change, and consequently, many were able to make positive changes to their lives. Ultimately, self-love, acceptance, self-esteem and confidence emerged as imperative to emotional wellness which materialized as an important criterion of successful aging.

## *Mental*

Within traditional models of successful aging discussions around mental health are often limited to maintaining high levels of cognitive functioning. Within this study, participants spoke about the importance of their mental health to their overall health, as it is just one component of their overall health. Commonly discussions around mental health were in relation to abstaining from drugs and alcohol in order to achieve a clear mind which emerged as a prerequisite to achieving mental health and wellness. The significance of drugs and alcohol on a participant's mental wellness is not surprising given that drugs and alcohol are frequently used by people experiencing illness, trauma and pain as a way to cope and alcohol abuse has a profound impact on an individual's ability to function (Reading, 2009).

Successful aging means to me is, being able to make proper decisions without the influence of alcohol or other substances, using my mind and my curiosity which is innate to me (Male, Native American, 53).

I managed to put down the ugly stuff [drugs], you know it was a rude awakening. It was a new life for me being diagnosed. You know, I don't think if I wasn't diagnosed maybe I wouldn't be here (Female, First Nations, Saskatchewan, 32).

I realized, I have a 12-year-old pit-bull and when I walk him down to the beach the last time I went into recovery I walked him down to the beach and I watched him jump into the water and he'd come out and he'd shake it all off and I went, that's what crack does to me! [Laughing] shake it all off, right, and so now I have had to find healthier ways to shake it all off! (Male, Métis, Ontario, 57).

Additionally, individuals expressed the value in finding purpose in their lives to improve their mental health and wellness. As is the case for many older adults with HIV, many participants spoke about the fact that they never thought they would live into their old age. "I never thought I would hit 30, I never believed I'd hit 40 and 50 I was like oh my god 60 is coming and sometimes the realization scares me "(Male, Métis, Ontario, 57). Consequently,

many older adults with HIV did not make plans for their future, as they did not think they would have a future. Now that these individuals are starting to accept the fact that they could now die of old age, they are recognizing the need to re-evaluate their lives. Re-evaluation of one's life was often discussed in relation to finding a purpose in life. Acceptance of this new reality and formulating a way to deal with this new reality surfaced as a fundamental component of reaching mental wellness and thus, successful aging.

Because I was, the majority of my life was outside of my community, I was actually of two different worlds, um, one was living in the main stream society as an aboriginal person and no one really liked it, no one really viewed me as part of their community. At the same time when I lived in my community, the aboriginal community, people saw me as white, so they didn't like me then. So I was balancing, or trying to balance out..., I am finding myself at my age now within the Aboriginal community, it is becoming more clear for me where I want to go and what I could contribute within my community. I am quite proud actually of being who I am and the age I am at. Yeah (Male, First Nations, British Columbia, 54).

I need to figure that out now that I am living longer what am I going to do with my life? Because before it was sort of like, you're on disability you have an income, you're getting sick the end result is you're going to die. Well, now that the medications are working better, people are being more smart about what they are doing, they are living way longer. So what do I - how do I - you know like everybody needs, has their own journey and their own path. Well if it's going to be a lot longer what do you do in that time? (Male, First Nations, Ontario, 50).

I'm to a point of self-determination where you know I envision being an old kookum, telling the stories to my grandchildren and my great grandchildren because that's what I want [crying] because that's what I want, you know? (Female, First Nations, Saskatchewan, 32).

In addition to achieving and maintaining a clear mind by abstaining from drugs and alcohol and re-evaluating life's goals and finding purpose in life, individuals also spoke about the importance of control and self determination to their mental health and wellness. The connection between control over factors impacting an individual's environment has been associated with health. Due to this connection, self-determination is becoming increasingly recognized as an important determinant to health and wellbeing (Reading, 2009).

I know, I think one of the things that I have learned is to be an advocate for myself in the health care system in particular and you can be a very good advocate because you know yourself better than everyone else does. So sometimes you just have to put your foot down and um and relationship building with um, the folks in the health care system has been has helped me I think age in a good way, successfully, healthy and kind of minimized the mental trauma of always having to see physicians (Female, Métis, unknown, 40).

Also for me, successful aging is really listening to my body and going to a doctor when I need to and going there with knowledgeable questions and not just taking their answers because sometimes the doctors may not know what they are doing and having to question them and be willing to fire a doctor, because I have fired a doctor and gone to other doctors because I felt that I wasn't getting my needs met by that particular doctor. So part of that means being engaged in my own health care (Male, Native American, British Columbia, 53).

By taking control over their health care and ultimately their lives, these individuals are demonstrating mastery. A high sense of mastery is correlated with higher levels of physical and mental health (Reading, 2009). In fact, in a study on protective risk factors associated with HIV stigma, Emlet et al. (2014) found mastery to be instrumental in minimizing HIV-related stigma in a population of older HIV positive adults in Ontario, Canada. In this study, while participants did not necessarily directly articulate how achieving a sense of purpose, control, self-determination and mastery improved their mental wellness they did see these factors as being important to their ability to actualize successful aging.

### ***Social Connectivity***

Engaging in social situations and maintaining social connectivity emerged as being instrumental to participant's spiritual, emotional, mental and physical health and wellness. Social connectivity could be viewed as the grass that weaves all of the other dimensions together. This is because opportunities for social engagement often provided subsequent opportunities for participants to practice their spirituality, and improve their emotional, mental, and physical

wellness by providing an outlet to engage with others. A study by Heckman et al. (2002) found that older adults with HIV who lacked social supports reported higher levels of psychological distress. Additionally, social support has been linked to lower levels of distress and positively impacting individual's dispositions (Sankar et al., 2011; Schrimshaw & Siegel, 2003).

Additionally, social engagement is a protective factor against social isolation, which is very common within the general aging population. Some studies have found that older adults with HIV are at more risk for social isolation than their HIV negative counterparts (Brennan-Ing et al., 2013; Solomon et al., 2013). The importance of building communities of mutual support to mitigate the risk of social isolation was recognized as a recurrent theme in Owen and Catalan's (2012) study on gay men aging with HIV.

Participants highlighted the positive impact that engaging with others had on their overall health and wellness. Engagement with others provided opportunities for individuals to learn, teach and share from one another's experiences. Most individual's experiences involving social connectivity and their explanations about how social cohesion positively impacted their wellness demonstrated opportunities where they could not only receive support but also provide support. Many experiences speak to both receiving and providing support both informally and formally, speaking to the idea of mutually supportive communities highlighted by Owen and Catalan (2012). Discussions on social connectivity can be organized into two categories:

### ***Opportunities for social support (learn and share)***

But seeing the similarities that we have in our journeys by communicating and talking is really important because you find out things that, and recognize that you are not going through it alone. Like for example on treatments, with \_\_\_\_\_ we found out that we are on the same treatments and are having the same symptoms. So it is really important to be able to have an open dialogue when I meet people and ask them from time to time, what are you on?



And sharing that and seeing whether or not it was the medications that was causing the symptoms or was it because of aging (Male, First Nations, Ontario, unknown).

I think to, learn from other people, like right here, most of the stuff that we are talking about, I think all of us feel, because we have been there somewhere at some point. And everybody thinks that you're alone but you're not, I mean I always think my life was tough but listening to other people's like I'm grateful (Male, Métis, New Brunswick, 52).

Well, when I think about that, I am alone out there in \_\_\_\_\_. Um, the only time, I really connect with people - with my peers, is when I attend conferences, like this, and the International Aids Conference, and that's if I get sponsored (Female, First Nations, British Columbia, 63).

I'm just so grateful to be here like physically at this CAAN event because my tank was empty, right, and to get here and to see everybody else wherever they are at, right, I remember when I was there, I remember when I felt that, I remember when I hated that, right, and um, it's amazing once I stopped hating myself how much I could love other people (Male, Métis, Ontario, 57).

I think having close friends, knowing that you have friends that are also living this life with you, sometimes you know it's easier to open and vent with them then it is with other people, because other people don't have to take ART's like you do, so like sometime you're tired, like today I'm just tired and lazy. Where they don't get it, that sometimes you just get tired. So it's easier to have friends that are living the same life, walking in similar paths, and kind of experiences. I'm older then \_\_\_\_\_ and she will ask me questions but I'll still ask her questions, she's been living with it longer. So we kind of like balance each other. And I have a few other friends too, that I can talk to, and ask questions, just like they do me. It's just balancing I guess, between us all (Female, Métis, Manitoba, 42).

I was diagnosed when I was 23, just about 24 years old and I gave myself like 5 years to live because I was so uneducated about it. And I didn't have a circle of support around me and you know if wasn't for events like this or ASO's like All Nations Hope, you know, being there with an open door to give me the tools to put in my tool kit, you know I wouldn't be here today (Female, First Nations, Saskatchewan, 32).

These quotes demonstrate the importance of social relationships which provide opportunities for individuals to learn from their friends who are also HIV positive as well community resources and organizations such as the Aids Service Organizations, All Nations Hope and the Canadian Aboriginal Aids Network. Furthermore, these quotes demonstrate the importance that individuals place on being able to share their knowledge

and experiences with others. Additionally, participants clearly highlighted the importance of attending conferences and engaging with ASO's for social participation. Many participants described mutually supportive relationships where they could learn from others as well as share their experiences with others who in turn may learn from them. So while the participants didn't directly identify teaching, they indirectly described it through the emphasis they placed on sharing their experiences such as their knowledge of various medications and symptoms with others.

### ***Opportunities to provide social support (teach and share)***

I mean I sit on very many, many community committees, provincially and nationally and that keeps me going, you know, it energizes me (Male, First Nations, British Columbia, 55).

So after I lost him I thought what am I going to do with myself? So that's when I started thinking, maybe I should start participating in these HIV programs and so I started participating and going to these conferences in \_\_\_\_\_ and then I started enjoying them so I asked if I could go to the ones out of town and my band started supporting me, I did a couple of presentations on HIV on the reserve, when I was living on the reserve because they wanted to let everybody know what HIV and one just a couple of years ago because they paid for me to go to a couple of conferences, so I went and did one a couple of years ago, so it was alright, I'm glad I got to tell my story, the way I grew up and stuff, I even got involved in gangs and stuff like that, but I put all of that behind me about 13 years ago and now I just want to continue on my journey for the rest of my life with helping other HIV + people and um, sharing my stories. I am just glad to be here (Male, First Nations, Manitoba, 51).

I go out to the schools in \_\_\_\_\_ the reserves around the area and I teach them about what it is like to live with HIV and I am always concerned about the younger generations. How are they going to, how are they going to handle their diagnosis? Or are they going to go to- who are they going to see. I think a lot of us think of our parents, when we are that age, we want to run to our parents. Some of us just don't have that, we don't have our mom and dads. But I think of them and I really, try to teach them to be cautious, you know, think twice before them, before they get into a high risk, you know, situation, to really stop and think (Male, Inuit, British Columbia, 53).

And I'm grateful for the creator, for the, because every time I wake up I thank god for my - for another day. And I am always thanking him for good health and praying that I will be doing more work with other people and helping them along their journey with HIV (Female, First Nation, British Columbia, 63).

So um, I have been positive for 19.5 years and they said I was on my way out, but twice actually, so I was diagnosed in January and then 4 months later I was put on the cocktail and I was on my way out again, but that didn't happen, the creator says you're not going anywhere, you've got work to be done and you need to stick around to help others and teach others (Male, First Nations, British Columbia, 55).

Successful aging is still feeling that I can contribute, successful aging is still loving myself and believing that I can still make a difference and do some good in the world, and successful aging is something I can pass onto the younger generation, and I am thinking about my children when I talk about this. What I can pass on the knowledge and experiences I've went through so they don't have to go through (Female, First Nations, Saskatchewan, 46).

These quotes demonstrate the significance of social opportunities which provide individuals with an outlet to teach others. These participants highlight the purpose and direction that being able to teach others about HIV gives them in life. Furthermore, many describe the obligation that they feel to teach others. Regardless of the motive: purpose or obligation, it is evident that social opportunities where individuals can teach others has a positive impact on one's health and wellness. Similar to the quotes which fall into the category of learning and sharing, these participants also highlight the importance of community engagement, attending conferences and utilizing ASO's, to create opportunities for social cohesion.

Opportunities for individuals to provide support whether it be to their peers who may be struggling with a diagnosis or medications, or to youth in their community, lent itself to opportunities to contribute to one's sense of generativity. Emlet (2008) found older adults can be motivated to disclose their positive status in order to be a positive role model to youth in order to contribute to their generativity. Similarly, in Lewis' (2012) study on successful aging with Alaska Natives, he found that the roles of Elders contributed to their sense of generativity. This study, similar to Lewis' (2012) found that many participants highlighted the importance of passing down their knowledge to youth. Additionally, opportunities to teach

and share contributed to an individual's purpose in life and mastery which is positively associated with better emotional and mental health outcomes. Much of the discussion on social connectivity centered on an obligation many individuals felt to share their life stories in order to teach others about HIV with the goal of reducing its subsequent spread in their communities. Ultimately, social engagement whether it took the form of learning, sharing or teaching proved to be a fundamental component to aging successfully with HIV.

### *Physical*

While the importance of physical functioning is central to traditional models of successful aging, participants in this research tended to place less emphasis on their physical health than they did on their spiritual, mental, emotional and social health and wellness. While the criteria for Rowe and Kahn's (1997) model of successful aging and most models that followed require the absence of disease and disability, participants did not view their disease as a barrier to successful aging. Rather, discussions on physical health typically related to treating one's physical body well through maintaining a well-balanced diet, engaging in physical activity, adhering to medications and using drugs and alcohol in moderation.

Aging with HIV is kind of going with it and taking care of yourself, medication wise, eating wise, exercise, rest, stuff like that. That's what pops into my head (Female, First Nations, Manitoba, 34).

I think it is really adhering to the treatments as well because I did have an episode where I decided to ugh, um, take a break from my treatment. And because I had heard other people had done it without any kind of repercussions or without any kind of you know, um, impact on their treatments and ugh, so I did it, but I got very, very ill and had to be hospitalized. Um, so I will not do that again. So my treatment is very important to me in terms of adhering and um, sometimes, I do have a tendency to ugh, to forget, my, my, my daily

treatment schedule and I try to, I try to stay on top of it as best I can (Female, First Nations, Quebec, 58).

I learned, to eat well, to eat healthy food...to try and eat so that I don't get diabetes which is really prevalent in our communities. And I think part of why diabetes is so prevalent in our communities is because of the poverty diet that people are forced to eat (Female, First Nations, Quebec, 58).

Exercise is my thing that really releases everything for me. I could be having the worst day possible and then I go to the gym and work out and it releases everything. It is really important (Male, Métis, New Brunswick, 52).

Discussions about physical health demonstrated that for many participants in this research, HIV is not their primary concern. For some, they are dealing with secondary illnesses which prove to be more debilitating than HIV.

It is not just the HIV but its diabetes, it's about losing my limb....and the nutrition thing (Male, unknown, Ontario, 63).

But I'm dealing with a secondary thing that has nothing to do with it, I have a spinal cord injury C5 C6 and I have a lot of problems from it, fibromyalgia and spasticity, so I'm, that's the problem, my HIV, my numbers are fabulous, so I am dealing with a secondary thing, that has nothing to do, and that bothers me more. My HIV is not my disability, my C5 C6 spinal fusion is, so I am dealing with something really different (Male, Métis, New Brunswick, 52).

When speaking about the importance of abstaining from drugs and alcohol in order to improve and/or maintain one's physical health, a sub-conversation about moderation developed.

I don't know, I'm really - like I've been positive for 22 years and I am really healthy, I just had a visit with my doctor and yet I go on these alcohol binges and drug binges once in a while and I just don't get it, why, you know? (Male, First Nations, unknown).

You know what the thing is, let me say something about that. There are no angels in this room, right? I mean, if you are doing well and you want to go out on a binge every now and again, as long as you are not doing it all the time to effect, please, I mean come on, we are not going on (Male, Métis, New Brunswick, 52).

I realized, I have a 12 year old pit-bull and when I walk him down to the beach the last time I went into recovery I walked him down to the beach and I watched him jump into the water and he'd come out and he'd shake it all off and I went, that's what crack does to me!

[Laughing] shake it all off, right, and so now I have had to find healthier ways to shake it all off! (Male, Métis, Ontario, 57).

So don't feel guilty, just don't overdo it! [Laughing]. What are you going to say? You got to be realistic about things (Male, Métis, New Brunswick, 52).

My definition of sobriety is without excess, right? (Male, Métis, Ontario, 57).

Moderation (Male, Métis, New Brunswick, 52).

Abstinence and sobriety are not synonymous (Male, Métis, Ontario, 57).

This dialogue demonstrates the supportive nature of the sharing circles and the camaraderie that evolved between participants. In fact, participants expressed gratitude for the opportunity to participate in this sharing circle as it provided them with an opportunity to learn, teach and share from one another. While many participants did discuss the connection between maintaining good physical health to their ability to age successfully, many were not able to separate their physical health from their overall health and wellness. The following quotes demonstrate how intricately connected these dimensions of health are to individual's beliefs about successful aging:

Yeah, so eating good, I've learned to eat good and I take care of myself, I um, I should be drinking more water than I am though, um, but overall I am eating good and I think that is really good to be able to take care of that part of you, but also take care of other parts of you, your spiritual, your emotional, your mental, and not just the physical, so all those pieces I try to take care of all that and it really helps to keep me healthy (Female, First Nations, Quebec, 58).

You know physically I feed myself darn good, you know, and that's - that's the way I see things and I understand and I learn is through that physical, mental, emotional and spiritual aspect (Female, First Nations, Saskatchewan, 32).

### *Successful Aging*

Throughout this study a categorical definition of successful aging was not established. Rather five dimensions of health emerged as being essential to one's ability to age successfully.

Ultimately, participants described successful aging as a subjective process. This process could be understood as a journey where the goal is to find a balance between spiritual engagement, emotional wellness, mental wellness, social cohesion and physical health. Participants' understandings and beliefs about successful aging clearly highlighted the fact that there was no standardized approach necessary to achieve health and wellness in each dimension. Nor is there a way to quantifiably measure one's engagement or success within each dimension. Participants did not dichotomize themselves or others as being either successful or unsuccessful, instead they described a fluid process which involved constant engagement and re-engagement with the five dimensions of health.

While the importance of these five dimensions of health and wellness clearly emerged throughout participant's descriptions of what successful aging meant to them, it became clear that as much as each dimension was distinct and had its own purpose, each dimension was also intricately connected. This became exceptionally clear during the analysis of the transcripts, especially when trying to compartmentalize quotes into each dimension. While many participants highlighted the interconnectedness of each dimensions, others did illustrate the importance of some dimensions in isolation. However, even when the latter is the case, it became clear how even if one dimension was not clearly linked to another, it often provides an opportunity to lead to another dimension. For example, when an individual engages socially, this may provide an opportunity to improve their physical health, whether through engaging in a group physical activity such as going on a walk, or enjoying cultural foods at a community potluck. In addition to providing an opportunity to socialize, attending ceremonies or church can contribute to one's spiritual health and wellness. Attending ceremonies and/or church can provide an opportunity for

the individual to learn from others and/or teach and share their knowledge with others, contributing to their mental health and wellness. Ultimately, the degree to which an individual will accept or embrace each dimension lies within the individual and therefore, will vary considerably.

Essentially, participants wove a story about personal and at times collective journeys with the aim of striking a balance between the five dimensions, in order to achieve a state of self-perceived health and wellness and alas, successful aging. It became evident that there was no way or no need to measure the degree to which an individual achieved health and wellness within each dimension or to judge when an individual reached a state of equilibrium between these dimensions, thus achieving successful aging. Conversely, participants highlighted the fact that the emphasis one places on each dimension is and should be subjectively determined. Therefore, successful aging is not reliant upon an equitable balance between dimensions and can be represented by an overemphasis on some and an under emphasis on others. Ultimately, there is no standardized approach or formula to achieve successful aging, at least not from the Indigenous epistemologies of these individuals living with HIV.

### ***Protective Factors***

In addition to the five dimensions of health which emerged as necessary components to successful aging, a number of protective factors were identified within this population. Within the aging and HIV literature it is recognized that as people age with HIV they develop vital coping mechanisms such as stigma management strategies. Additionally, a number of protective factors which contribute to better physical and mental health outcomes in older individuals living



with HIV exist within the population. Within this study resilience, age, and culture have been identified as protective factors inherent to this population.

### *Resilience*

The ability to adapt despite experiences of adversity constitutes resilience. It is likely that there may be factors inherent in an older HIV positive person which facilitate psychological adjustment to their diagnosis (Siegel, Raveis & Kraus, 1998). Similarly, Vance et al. (2011) found this to be the case in his study on Hardiness, Successful Aging and HIV. More specifically, Vance et al. (2011) postulated that an HIV diagnosis represents a life event that can facilitate growth and maturity.

Within this study, the term resilience did not actually come up directly in either the sharing circles or interviews, however, participant's stories commonly demonstrated resilience. Resilience was evident through stories which described participant's experiences with trauma, racism, addictions, HIV stigma, and homophobia. While experiences with trauma, racism, addictions, HIV stigma and homophobia were common, equally so were participant's experiences with overcoming these challenges. Despite compounding layers of stigma and adversity experienced throughout the life course, individuals within this study demonstrated profound abilities to not only adapt to these challenges but to overcome these challenges. In overcoming challenges, participants demonstrated vital stigma management strategies and strength which they had acquired over their lives.

And where I am at now, I am in my 9th year of living with the virus, my 9th birthday and um, like really right now, I pick up colds kind of easy but I feel good, except for the

stigma and the discrimination. That's the ugly of it right now... I live with issues more than just HIV, you know I have reconciliation issues with my children, I am intergenerationally impacted [crying] fighting other circles, dealing with missing and murdered Indigenous women, you know all of those things, I don't want to be further stigmatized or treated more with bias because I don't want to take the damn medications yet... That's where I am at in my life. People try to be discriminatory or take away my value or you know my voice, you know, who I am as a positive Aboriginal woman, I'll be fine and dandy. You know, I'll be walking around like superwoman and I'll be just fine (Female, First Nations, Saskatchewan, 32).

I have been HIV + and HEP C + for 15 years and I lost both of my parents, I was in child and family services from the age of 12 to the age of 18. Separated from all of my brothers and sisters. Then when I got out of the child and family services I started drinking heavy and started hanging around the streets, started getting into alcohol and drugs..., but I put all of that behind me about 13 years ago and now I just want to continue on my journey for the rest of my life with helping other HIV + people and um, sharing my stories. (Male, First Nations, Manitoba, 51).

While the above quote clearly highlights the layers of stigma and discrimination that one faces as an Indigenous person living with HIV, and the adversities almost inherent to the Indigenous population such as intergenerational trauma, powerfully, these quotes demonstrate resilience in the face of adversity. Despite all of the issues that the 32-year-old First Nations woman is dealing with she describes herself as walking about like superwoman, telling us that she will be just fine.

I would argue that resilience is an inherent quality in the Indigenous population of Canada, demonstrated by their very existence despite the legacy of cultural genocide and assimilation policies in this nation. Additionally, current research has also identified resilience within the aging HIV positive population. Combined, as older Indigenous peoples living with HIV, this population represents an extremely resilient group of individuals who have many lessons to offer with regards to successful aging to Indigenous and non-Indigenous and HIV positive and negative peoples alike.

## *Age*

With older age and a longer time since diagnosis, individual's capacity to confront challenges such as accessing care and services will likely increase (Siegel et al., 1998). Poindexter and Shippy (2010) have also identified age as a protective factor for resisting stigma in older adults with HIV. Age and maturity shapes individuals experiences of living with HIV and advanced age and maturity can provide advantages to one's ability to cope with the challenges associated with aging with a highly stigmatizing disease (Siegel et al., 1998). In Siegel et al.'s (1998) study on the perceived advantages and disadvantages of age among older HIV positive adults, a number of key advantages were identified which are pertinent to this study. First, "With age comes wisdom, greater resourcefulness and superior problem solving skills as a result of typically having to confront a great number of diversity of problems and crises", second, "with age comes greater respect for life and health", and third, "older people are less psychologically threatened by disability and fatigue" (Siegel et al., 1998). Emlet et al. (2013) identified being older and a longer time since HIV diagnosis to be associated with lower levels of enacted and internalized stigma. This is likely due to the fact that the longer a person lives with HIV, HIV may become less of a focus in an individual's life and, thus, less internalized. Our research supports Siegel et al.'s (1998) and Emlet et al. (2013) findings that age can be a protective factor to coping and aging well with HIV.

Additionally, Indigenous cultural conceptions of age may provide another advantage to older age within the HIV positive Indigenous population, which may be unique to this population. Within many Indigenous groups the term "older" and "Elder" should not be used

interchangeably, this is because “older” refers to chronological age, whereas “Elder” denotes an individual who has attained a status of honour, wisdom and respect, regardless of their chronological age (Wilson et al., 2011). According to the Royal Commission on Aboriginal Peoples (1996), “the term Elder is used in an Aboriginal context to describe someone who is a cultural and spiritual guide and who has insights, understandings, and communication abilities to transmit the wisdom of previous generations”. While not all older Indigenous peoples will achieve Elder status, older Indigenous adults are still given a special status and are highly respected members of their communities who are recognized as being able to contribute in ways which are consistent with traditional roles (Baskin & Davey, 2015). This notion of “Elderhood” and subsequent respect and valuation of all older adults within Indigenous cultures demonstrates another protective factor for this population.

I don't know if I have ever been discriminated against because of my age, within my community. I have been discriminated against because of the HIV but not so much about the age because people that are aging with HIV, it's very different for us because we are growing into becoming Elders and there are young Elders to like, it's not necessarily an age thing, there could be a 50 year old or a 45 year old that is recognized as an Elder in our community, so Elders are very revered, so I don't think I've ever had any discrimination because of my age and I am very lucky to say that...I really feel sometimes that I am growing into my Elderhood. Elders are respected in our culture, so I really feel like I am growing into that as I age with HIV. And the HIV part of it actually is, I don't shy away from disclosing, I am publicly disclosed about my HIV and in terms of embracing my Elder – Elderhood, as I'm aging I feel like they are beginning to recognize me as entering that period of my life and because Elders are for the most part very respected in our culture it helps a little bit. It helps me to be able to have a conversation with somebody one on one about HIV, so maybe it helps in terms of you know that respect that people have for Elders in our communities, that I am being seen as an Elder despite the fact that I am HIV positive. I don't see myself as an elder yet but I feel that I am a lot calmer now then I used to be, 10 years ago for instance like I think I was quite vocal. So, as I age I'm learning to kind of be more balanced (Female, First Nations, Quebec, 58).

This participant clearly demonstrates how the notion of Elderhood and by extension, Indigenous conceptualizations of age provide a buffer for discrimination, thus acting as a

protective factor, buffering individuals from barriers and challenges they may experience on their journey's to age successfully with HIV.

Women or men who are living with HIV and aging with HIV have that one more element to offer in the wisdom that they bring to the table as Elders and as old people. They have one more thing, one more gift to share, and to utilize in their personal journey, and so, I think I heard \_\_\_\_\_ say it, but I've heard other people say it along the way that the HIV has been a gift for them, but it's not just as a gift for those people who are the recipients of the virus or the person that is carrying the virus but rather it's a gift to those of us in your world because you share the wisdom that you bring as a direct result of having had that lived experience (Female, Elder, Saskatchewan).

While this quote was not from one of the participants, rather the Elder in our sharing circle with women, I think it is important to include because it highlights the wisdom and knowledge that participants have acquired throughout their lives not necessarily due to their Indigently or age but as a result of their diagnosis. But combined, this point demonstrates the knowledge and wisdom that HIV positive Indigenous peoples have because of their lived experiences as Indigenous peoples aging with HIV, and consequently the ability that these individuals have to teach others through the sharing of their stories.

Throughout the data collection phase of this study it became apparent that chronological age was not important or necessary to individual's conceptualization of "older adults" or "successful aging". While the inclusion criteria for our study aimed to speak to "older adults" defined as those over the age of 50, participants under the age of 50 were included. This is because despite the fact that we advertised that we were looking for "older adults", individuals under the age of 50 came forward and wanted to participate.

And thank you for having me and my children here. This aging is very important to me. I'm glad that being 32, you guys are welcoming me here because I thought that it was for older women. But you know what, I totally plan on being old, living with this. And it is

something important, and you know, this is where I am supposed to be... I envision being an old kookum, telling the stories to my grandchildren and my great grandchildren because that's what I want [crying] because that's what I want, you know? (Female, First Nations, Saskatchewan, 32).

When I meet my brothers and sisters over 50 I get lots of wisdom from them because I hear what they say and at some point I know that I am going to reach that point where I'll have moments of clarity, and like wow, now I will know what they meant when they were talking like that because sometimes I'm like what? [laughing]. (Male, First Nations, Ontario, age unknown).

Ultimately, "old age" was not viewed as synonymous with a chronological age over 50.

Individuals eager to participate in the study spoke about the fact that they were all aging and they wanted the opportunity to learn from the wisdom of their Indigenous brothers and sisters who were over the age of 50. Additionally, some participants spoke about the fact that their biological age was older than their chronological age due to the effects HIV and ART's have had on their bodies.

### *Culture*

Within the aging and HIV literature it is recognized that, "like the process of aging itself, HIV is shaped more by the individual's social, physical, cultural, and economic setting than by biological senescence" (Sankar et al., 2011, p.1203), this implies that cultural beliefs can greatly impact an individual's experience of aging with HIV. Furthermore, cultural beliefs can create barriers to an individual's ability to age successfully, or alternatively, these beliefs have the ability to facilitate successful aging. Fleming and Ledogar (2008) have identified four cultural factors (spirituality, traditional activities, traditional languages, and traditional healing) as being protective factors of resilience. Fleming and Ledogar (2008) have demonstrated the connection

between Indigenous spirituality and culture and health and healing. Additionally, Indigenous professionals are increasingly recognizing traditional spirituality and culture as effective responses to historical trauma and unresolved grief. Within this study, culture often in the form of spirituality emerged as a protective factor, often acting as a facilitator to successful aging.

What I see in my life is I see my traditional way of life and ways of knowing which totally speak to me, give me life, give me self-determination give me strength, give me empowerment and you know, continue to build on my resiliency (Female, First Nations, Saskatchewan, 32).

We are going through this whole transition and reclaiming our culture and getting our culture back. I think that is a very important part within my life because I was raised as a Christian but now I am learning more about my traditional background and its really helped me, I guess in the healing process, to open my mind and to help me gain wisdom and be more mindful, be more aware, ugh, and take pride in who I was to be proud to be Anishinabek and recognize that we have all these inherent gifts and part of my journey is to become - to search for that as I am aging (Male, First Nations, Ontario, age unknown).

While Sankar et al., (2011) suggested that older adults may be able to achieve culturally appropriate late life stage goals only if their HIV diagnosis remain undisclosed, this research suggests otherwise. The aforementioned discussion on Indigenous conceptualizations of age and the respect for Elders as well as older Indigenous peoples in general provides the basis for an argument against Sankar et al.'s (2011) finding. In fact, participants described opportunities they now felt they had to accomplish culturally specific late life stage goals such as the transmission of knowledge to younger generations as a consequence of their diagnosis. Emlet (2008) also found that generativity motivated older HIV positive adults to disclose their status, as a way to role model responsible behaviour to younger generations.

Sometimes I like to think of myself as a kind of ambassador in terms of you know, my aging and being able to speak to people and be honest about it with them when I talk about HIV, so I think there is a role for us as we age within our community and I think that's that role, and it might not be for everyone, there might be others that might not be

able to disclose their HIV status but I do...So, it's very different, ugh, I think, it's very different somehow, for us, because of our cultural values and our traditions, and I think there is a way to actually, to bring that somehow, because of that, because of our values, our community values, our Indigenous values and our values from family, I think its unique in that way. I'm not trying to sugar coat it at all because there are still instances where people do discriminate and as an Aboriginal person living with HIV, like if I were to be living in my home community, which I did when I first got diagnosed, everybody knows everybody's business there, but what I did was I stood tall and I walked tall, despite the fact that I was living with HIV and so people start to engage with me and it was good (Female, First Nations, Quebec, 58).

I could see myself and recognize as one, having a male physical presence, but at the same time having both a male and female spirit, mindset, and that allows me to get into community organizations to work with all of our people as opposed to working with one specific group. An example is my work history has allowed me to work with, for the first time in an organizations history in Vancouver, for me to work in an all woman's organization, to work with women and children from abusive relationships into transitioning into their own lives. and that was an honour because I spoke with the executive director and explained what was going on in terms of "two-spiritness", and how I understood it, and how it could benefit, which is something that was revered in our community historically. So taking all of that and then of course my lived experience, it's a strict balance for me. As I get older...I think if I maintain a level of understanding of what my capabilities are, and teaching our community, to work with our community, you know, the door is wide open (Male, First Nations, British Columbia, 54).

This participant describes how Indigenous cultural beliefs about “two-spiritness” have provided him with an opportunity to fulfill culturally appropriate life stages such as teaching within the community. Ultimately, culture has been recognized as an important component to health and wellness within the Indigenous population, and this study supports this finding. More specifically, this study provides support for the notion that culture represents a protective factor for resilience and by extension successful aging. Culture provides a pathway for many to find purpose in their lives often during times of existential crises many are facing as a consequence of their diagnosis and subsequent survivor guilt.

While resilience, age, and culture were each analyzed separately as protective factors, similar to the dimensions of successful aging outlined above, these three factors are also



intricately connected. It is clear that culture is a protective factor for resilience, and age provides a buffer for stigma and discrimination due to Indigenous cultural conceptualizations of age and the notion of Elderhood. Regardless of whether or not these protective factors are in isolation from one another or are in relation to one another, they all act as facilitators to successful aging.

## Chapter Six: Conclusion

The goal of this study was to explore what successful aging means to Indigenous peoples aging with HIV/AIDS. What emerged from this research was a culturally resonate framework (see Appendix D) for successful aging which is congruent with Indigenous notions of health and wellness. The findings from this research fill a gap in the HIV and aging literature, contributing findings related to HIV positive Indigenous people's understandings and experiences with successful aging. Additionally, findings from this study are important to the further development of the successful aging discourse in the field of social gerontology. As previously identified, there is currently a lack of cultural breadth within the successful aging framework, and importantly, this research can contribute to this discourse.

The need for CBPR which integrates Indigenous knowledge and methodologies is essential to the success of Indigenous health research and the subsequent health services, policies and programs which may develop from this research. For far too long Indigenous health research has been conducted ON Indigenous peoples rather than WITH Indigenous peoples. This legacy of unethical research has been damaging in myriad ways including but not limited to: the misrepresentation of research findings, misappropriation and commodification of Indigenous knowledge, unauthorized secondary use of data and the outcomes of such research has often resulted in various forms of harm (Castleden et al., 2010). Combined with the legacy of colonization in this country, Indigenous peoples are in a state of cultural disaray, experiencing collective trauma and grief which has mainfested into a number of health problems (Reading, 2009). Despite the exhaustive amount of research that has been done ON Indigenous peoples health, Indigenous peoples still experience disproportinate rates of chronic and infectious

diseases, higher rates of substance abuse, suicide and addictions as well as an overall lower life expectancy than their non-Indigenous Canadian counterparts (Adelson, 2005). Therefore, current approaches are inadequate and something needs to change.

Self-determination and cultural resonance are necessary factors for effective health research and the resulting services, policies and programs. Indigenous frameworks for successful aging needs to come from the words and lived-experience of Indigenous peoples living and aging with HIV/AIDS. It is only from these words that effective health interventions which may aid this population to age successfully can be created. This study offers a successful aging framework which does just that, incorporates the voices of the individuals who this research is about. The research and resulting development of an Indigenous model of successful aging was created based on the voices of this very population. The individuals involved in this study represent the fore-runners of the greying of the epidemic, so there is still much to learn. This study provided an opportunity for these fore-runners to benefit from the knowledge and support gained from one another throughout this study. Additionally, this study will provide other younger and newly diagnosed individuals with important knowledge which may help them navigate learning to age successfully with HIV.

While recognizing the strengths and identifying the coping mechanisms already present in this population was the focus of this study, barriers to successful aging were also identified throughout this study. Even though barriers and challenges to successful aging with HIV were not the focus of this study, it is important to recognize and understand that these barriers and challenges exist in order to come up with effective strategies which can help to facilitate

successful aging within this population. Within the sharing circle with service providers, participants described poverty as a major barrier to successful aging for their clients. This was echoed by the men and women in our sharing circles who spoke about a lack of access to social determinants of health as a barrier to successful aging. It is important to note that participants did not view HIV/AIDS itself as a barrier to successful aging, it was a lack of access to the basic social determinants of health as a barrier. Additionally, some participants spoke about the stigma and discrimination they experience in the health care system as another barrier to successful aging. Lastly, some participants saw a lack of access to traditional medicine, food and healers as additional challenges to their ability to age successfully with HIV.

Service providers were asked about a “wish-list” of resources they could use to provide care to their clients in order to help them age successfully with HIV/AIDS. Items on their “wish-list” were congruent with the HIV positive men and women in this study’s perceptions on successful aging. For example, service providers wished for increased opportunities for social participation, access to transportation, food, adequate income, housing and access to culturally sensitive and discriminatory free care. A lack of access to transportation posed a major barrier to accessing many of the resources necessary to facilitate successful aging such as access to food, social opportunities and health services. While transportation was a major barrier it was also viewed as an easy solution to a lot of the other barriers as increased access to transportation could help increase opportunities for social participation, access to food and health care services (traditional and bio-medical). These barriers need to be recognized as priorities in the programs, services and policies which are being offered and made to support this population.

In order to minimize these barriers to help facilitate successful aging within this population, there are a number of recommendations relevant to research and policy which have been developed based on the discussions had with Indigenous peoples living with HIV/AIDS and service providers providing care to this population.

### **1. Increased access to high quality health care:**

While the need for access to culturally competent health care is paramount, it is hard to advocate for cultural competency when there is still a lack of access to health care in general. Before health care can be culturally competent, care needs to actually be available. Due to geographic and jurisdictional barriers, many Indigenous peoples experience inequitable access to health care. When access to care as a result of geographic and/or jurisdictional barriers is not an issue, many Indigenous peoples continue to face barriers due to lack of culturally competent care, lower levels of education and/or income and experiences of racism and discrimination in the health care system (PHAC, 2014). In addition to increased access to mainstream health care services, access to traditional Indigenous medicine, healing practices and Elders needs to be increased. Similar to the Truth and Reconciliation Commission (TRC) Calls to Action (2015) regarding health, this research recommends an increase in the collaboration between the Canadian health-care system and Indigenous healing practices in the treatment of Indigenous peoples in collaboration with Indigenous healers and Elders, if requested. In order to increase the level of cultural competency within the health care system this research supports the TRC's (2015) further calls to action to: (1) increase the number of Indigenous health care professionals and service providers, (2) safeguard the retention of

Indigenous health-care providers in Indigenous communities, and (3) make cultural competency training mandatory for all healthcare professionals.

## **2. Increased funding:**

In order to reduce barriers to successful aging such as the above recommendation to increase access to quality (culturally competent) health care, and to basic social determinants of health an increase in funding for Indigenous health services is necessary. This research supports the TRC's (2015) call to action regarding the government's responsibility to provide sustainable funding for new and existing Indigenous health centers. Health care in Canada for Indigenous peoples is characterized by jurisdictional confusion causing problems with regards to access, service delivery and fragmented funding for Indigenous health between federal and provincial health providers (HCC, 2013). Primary health care services for on-reserve First Nations are under federal jurisdiction whereas primary health care for other Canadians are under provincial jurisdiction. The varying levels of involvement of federal, provincial and territorial levels of government results in a highly complex and uncoordinated system characterized by gaps in services. Indigenous peoples without status are also denied access to certain health care services such as access to HIV treatment under the Non Insured Health Benefit (NIHB) program (Gabel, Jackson, & Ryan, 2016). In order to improve and create equal access to the health care services that Indigenous peoples have access to, such as HIV treatment, more funding is needed. Additionally, self-determination needs to be recognized as a priority for greater control over allocation of funds and provision of health care services on reserve. Indigenous peoples must have greater control over the spending on health care

services that directly impact their health.

### **3. Increase in Indigenous led, decolonizing research:**

While this research provides a solid starting point for HIV and aging research from an Indigenous perspective, further research is needed. It is imperative that this research adopts a CBPR approach incorporating Indigenous voices and Indigenous knowledge. “In other words, it is necessary (and morally and ethically sound) to create understanding from within the world views, perspectives and value system of a people who originally experienced the phenomena in the first place” (McLeod, 2007 as cited in Gabel, Jackson & Ryan, 2016, p.12). An approach which uses Indigenous knowledge is necessary to stop the further perpetuation of colonial ideologies which continue to result in negative health outcomes for Indigenous peoples. Such research can provide a more holistic understanding of the ways Indigenous peoples living with HIV experience aging. Further research is needed that explores more fully how older Indigenous men and women may experience aging with HIV differently. Additionally, research which explores potential differences in the ways First Nations, Inuit and Métis people living on and off reserve experience aging with HIV is also important. Research which recognizes the heterogeneity of the aging, HIV positive Indigenous population creates a space for the possibility that resulting programs, services and policies may be more respectful of self-determination and more culturally competent.

Acting upon these recommendations may increase the likelihood for the successful development and implementation of programs, services, and policies which can help facilitate successful aging within this population. Despite the fact that Indigenous peoples with HIV are

resilient individuals and are proving to already be aging successfully with HIV/AIDS regardless of the number of challenges they continue to face, creating culturally resonate programs, services and policies which can help facilitate the successful aging process demonstrates a step towards reconciliation. Given that the poor status of so many Indigenous peoples health is a direct result of the Canadian governments colonial policies such as the Indian Act and the residential school system, Canada has a moral and ethical, if not completely legal obligation to work collaboratively with Indigenous peoples providing them with the resources they need to age successfully, with or without HIV. Successful aging should be a lifelong process, and who better to learn from then the individuals in this study who are aging successfully despite long lives filled with what many would consider insurmountable challenges.



## References

- Aboriginal Peoples in Canada: First Nations People, Metis and Inuit. (2015). *Statistics Canada*.  
<https://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.cfm>
- Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, S45-S61.
- Barton, SS (2004). Narrative inquiry: Locating Aboriginal epistemology in a relational methodology. *Journal of Advanced Nursing*. 45, 5, 519-526.
- Balderson, B. H., Grothaus, L., Harrison, R. G., McCoy, K., Mahoney, C., & Catz, S. (2013). Chronic illness burden and quality of life in an aging HIV population. *AIDS care*, 25(4), 451-458.
- Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. *Successful aging: Perspectives from the behavioral sciences*, 1(1), 1-34.
- Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-eyed seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2(4), 331-340.
- Bartlett, J. G., Iwasaki, Y., Gottlieb, B., Hall, D., & Mannell, R. (2007). Framework for Aboriginal-guided decolonizing research involving Métis and First Nations persons with diabetes. *Social Science & Medicine*, 65(11), 2371-2382.
- Barton, Sylvia S. (2004). Narrative inquiry: locating Aboriginal epistemology in a relational Methodology. *Journal of Advanced Nursing*, 45(5), 519–526.

- Beaulaurier, R. L., Craig, S. L., & De La Rosa, M. (2008). Older Latina women and HIV/AIDS: An examination of sexuality and culture as they relate to risk and protective factors. *Journal of gerontological social work, 52*(1), 48-63.
- Beuthin, R. E., Bruce, A., & Sheilds, L. (2015). Storylines of Aging With HIV Shifts Toward Sense Making. *Qualitative health research, 25*(5), 612-621.
- Bhavan, K. P., Kampalath, V. N., & Overton, E. T. (2008). The aging of the HIV epidemic. *Current HIV/AIDS Reports, 5*(3), 150-158.
- Braun, K. L., Browne, C. V., Ka'opua, L. S., Kim, B. J., & Mokuau, N. (2014). Research on indigenous elders: From positivistic to decolonizing methodologies. *The Gerontologist, 54*(1), 117-126.
- Brennan, M. (2008). Older men living with HIV: The importance of spirituality. *Generations, 32*(1), 54-61.
- Brennan, D. J., Emlet, C. A., & Eady, A. (2011). HIV, sexual health, and psychosocial issues among older adults living with HIV in North America. *Ageing International, 36*(3), 313-333.
- Brennan-Ing, M., Seidel, L., London, A. S., Cahill, S., & Karpiak, S. E. (2014). Service utilization among older adults with HIV: The joint association of sexual identity and gender. *Journal of homosexuality, 61*(1), 166-196.
- Brown, D. R., & Sankar, A. (1998). HIV/AIDS and aging minority populations. *Research on Aging, 20*(6), 865-884.
- Cahill, S., & Valadéz, R. (2013). Growing older with HIV/AIDS: new public health challenges. *American journal of public health, 103*(3), e7-e15.

- Castleden, H., Morgan, V. S., & Neimanis, A. (2010). Researchers' perspectives on collective/community co-authorship in community-based participatory indigenous research. *Journal of Empirical Research on Human Research Ethics*, 5(4), 23-32.
- Cammer, A. L. (2006). Negotiating culturally incongruent healthcare systems: The process of accessing dementia care in Northern Saskatchewan.
- Canadian Aboriginal AIDS Network. (2009). *Aboriginal Strategy on HIV/AIDS in Canada II: For First Nations, Inuit and Metis Peoples from 2009 to 2014*. Ottawa, Ontario.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (2010). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
- Canada. International Indigenous Working Group on HIV/AIDS. *Toronto Charter: Indigenous Peoples Action Plan on HIV/AIDS*. Toronto, Ontario, 2006.
- Crisologo, S., Campbell, M. H., & Forte, J. A. (1996). Social work, AIDS and the elderly: Current knowledge and practice. *Journal of Gerontological Social Work*, 26(1-2), 49-70.
- Crowther, Parker, Achenbaum, Larimore, & Koenig, 2002)
- David, M., & Sutton, C. D. (2011). *Social research: An introduction*. Sage.
- Deeks, S. G., & Phillips, A. N. (2009). HIV infection, antiretroviral treatment, ageing, and non-AIDS related morbidity. *BMJ: British Medical Journal*, 288-292.
- Denzin, N. K., & Lincoln, Y. S. (2008). *Handbook of critical and indigenous methodologies*. Sage.
- Douglas, V. (2013). Introduction to Aboriginal Health and Health Care in Canada. New York, New York: Springer Publishing Company. (pgs. 21-35).

- Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2008). Over fifty and living with HIV in London. *Sexually transmitted infections*, 84(6), 468-472.
- Ellman, T. M., Sexton, M. E., Warshafsky, D., Sobieszczyk, M. E., & Morrison, E. A. (2014). A Forgotten Population: Older Adults with Newly Diagnosed HIV. *AIDS patient care and STDs*, 28(10), 530-536.
- Emlet, C. A. (2004). HIV/AIDS and aging: A diverse population of vulnerable older adults. *Journal of human behavior in the social environment*, 9(4), 45-63.
- Emlet, C. A. (2006). "You're awfully old to have this disease": Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *The Gerontologist*, 46(6), 781-790.
- Emlet, C. A. (2007). Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS patient care and STDs*, 21(10), 740-752.
- Emlet, C. A. (2008). Truth and consequences: A qualitative exploration of HIV disclosure in older adults. *AIDS care*, 20(6), 710-717.
- Emlet, C. A. (2014). Current knowledge and future directions on aging and HIV research. *Behavioral Medicine*, 40(3).
- Emlet, C. A., Brennan, D. J., Brennenstuhl, S., Rueda, S., Hart, T. A., & Rourke, S. B. (2013). Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. *AIDS care*, 25(10), 1330-1339.
- Emlet, C. A., & Farkas, K. J. (2005). A descriptive analysis of older adults with HIV/AIDS in California. *Social Work Diagnosis in Contemporary Practice*, 369.

- Emlet, C. A., Fredriksen-Goldsen, K. I., & Kim, H. J. (2013). Risk and protective factors associated with health-related quality of life among older gay and bisexual men living with HIV disease. *The Gerontologist*, 53(6), 963-972.
- Emlet, C. A., & Shippy, R. A. (2008). Chapter 6; HIV/AIDS Treatments. *Journal of gerontological social work*, 50(S1), 131-149.
- Emlet, C. A., Tozay, S., & Raveis, V. H. (2010). "I'm Not Going to Die from the AIDS": Resilience in Aging with HIV Disease. *The Gerontologist*, gnq060.
- The Federal Initiative to Address HIV/AIDS in Canada. (2004). *Canada Public Health Association*. Retrieved from [http://www.cpha.ca/uploads/portals/hiv/federal\\_initiative\\_e.pdf](http://www.cpha.ca/uploads/portals/hiv/federal_initiative_e.pdf)
- Fleming, J., & Ledogar, R. J. (2008). Resilience, an evolving concept: A review of literature relevant to Aboriginal research. *Pimatisiwin*, 6(2), 7.
- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans' management of HIV/AIDS stigma. *AIDS care*, 21(10), 1306-1312.
- Furlotte, C., Schwartz, K., Koornstra, J. J., & Naster, R. (2012). 'Got a room for me?' Housing Experiences of Older Adults Living with HIV/AIDS in Ottawa. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 31(01), 37-48.
- Gabel, Jackson & Ryan. (2016). Do it in a Good Way: Recommendations for Research and Policy in Indigenous Communities Aging with HIV/AIDS. Suzanne Hindmarch, Michael Orsini and Marilou Gagnon. Seeing Red: HIV/AIDS and Public Policy in Canada. Accepted, University of Toronto Press, Canada
- Ganann, R., Ciliska, D., & Thomas, H. (2010). Expediting systematic reviews: methods and implications of rapid reviews. *Implementation Science*, 5(1), 1.

- Genke, J. C. (2000). HIV/AIDS and older adults: The invisible ten percent. *Care Management Journals*, 2(3), 196.
- George-Kanentiio, Doug. (2000). Iroquois Culture and Commentary. Santa Fe, New Mexico: Clear Light Publishers.
- Golub, S. A., Botsko, M., Gamarel, K. E., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2013). Dimensions of psychological well-being predict consistent condom use among older adults living with HIV. *Ageing international*, 38(3), 179-194.
- Goodroad, B. K. (2003). HIV and AIDS in people older than 50: A continuing concern. *Journal of gerontological nursing*, 29(4), 18.
- Grov, C., Golub, S. A., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS care*, 22(5), 630-639.
- Haile, R., Padilla, M. B., & Parker, E. A. (2011). 'Stuck in the quagmire of an HIV ghetto': the meaning of stigma in the lives of older black gay and bisexual men living with HIV in New York City. *Culture, health & sexuality*, 13(04), 429-442.
- Hampton, M. C., Halkitis, P. N., Perez-Figueroa, R., & Kupprat, S. A. (2013). Religiousness, Spirituality, and Existential Well-being Among HIV-Positive Gay, Bisexual, and Other MSM Age 50 and Over. *Journal of Religion, Spirituality & Aging*, 25(2), 160-176.
- Hansen, N. B., Harrison, B., Fambro, S., Bodnar, S., Heckman, T. G., & Sikkema, K. J. (2013). The structure of coping among older adults living with HIV/AIDS and depressive symptoms. *Journal of health psychology*, 18(2), 198-211.
- Health Council of Canada. (2013). Canada's most vulnerable: Improving health care for First Nations, Inuit, and Métis seniors, H.C.o. Canada: Toronto, ON.

- Heckman, T. G., Kochman, A., Sikkema, K. J., & Kalichman, S. C. (1999). Articles-Depressive Symptomatology, Daily Stressors, and Ways of Coping Among Middle-Age and Older Adults Living With HIV Disease. *Journal of mental health and aging*, 5(4), 311-322.
- Heckman, T. G., Heckman, B. D., Kochman, A., Sikkema, K. J., Suhr, J., & Goodkin, K. (2002). Psychological symptoms among persons 50 years of age and older living with HIV disease. *Aging & mental health*, 6(2), 121-128.
- HIV/AIDS Epi Updates. (2010). *Public Health Agency of Canada*. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/6-eng.php>
- HIV/AIDS Epi Updates. (2014). *Public Health Agency of Canada*. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/6-eng.php>
- Hughes, Megan L. (2006). Critical Incident stress debriefing as a trauma intervention in First Nation Communities. *Canadian Journal of Counselling*, 40(2), 82-95.
- Jackson, Randy, Debassige, Corena, Masching, Rene, & Whitebird, Wanda. (2014). Towards an Indigenous narrative inquiry: The importance of composite, artful representations. In Christina Sinding & Hazel Barnes (Eds.), *Social Work Artfully Beyond Borders and Boundaries* (pp.135-158). Waterloo, ON, Canada: Wilfrid Laurier University Press.
- Jang, H., & Anderson, P. G. (2011). Aging and living with HIV/AIDS. *Journal of gerontological nursing*, 37(12), 4.
- Justice, A. C. (2010). HIV and aging: time for a new paradigm. *Current HIV/AIDS Reports*, 7(2), 69-76.
- Kahana, E., & Kahana, B. (2001). Successful aging among people with HIV/AIDS. *Journal of Clinical Epidemiology*, 54(12), S53-S56.

- Kahana, E., & Kahana, B. (1996). Conceptual and empirical advances in understanding aging well through proactive adaptation.
- Kalichman, S. C., Heckman, T., Kochman, A., Sikkema, K., & Bergholte, J. (2014). Depression and thoughts of suicide among middle-aged and older persons living with HIV-AIDS. *Psychiatric Services*.
- King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *The Lancet*, *374*, 76-85.
- Kuteesa, M. O., Wright, S., Seeley, J., Mugisha, J., Kinyanda, E., Kakembo, F., & Scholten, F. (2014). Experiences of HIV-related stigma among HIV-positive older persons in Uganda—a mixed methods analysis. *SAHARA-J*, *11*(1), 126-137.
- Lane, A. M., Hirst, S. P., & Reed, M. B. (2013). Housing options for North American older adults with HIV/AIDS. *Indian Journal of Gerontology*, *27*(1), 55-68.
- Lavallee, L. F. (2009). Practical application of an Indigenous research framework and two qualitative Indigenous research methods: Sharing circles and Anishnaabe symbol-based reflection. *International Journal of Qualitative Methods*, *8*(1), 21-40.
- Lewis, J. P. (2011). Successful aging through the eyes of Alaska Native elders. What it means to be an elder in Bristol Bay, AK. *The Gerontologist*, *51*(4), 540-549
- Liang, J., & Luo, B. (2012). Toward a discourse shift in social gerontology: From successful aging to harmonious aging. *Journal of Aging Studies*, *26*(3), 327-334.
- Levy-Dweck, S. (2005). HIV/AIDS fifty and older: A hidden and growing population. *Journal of Gerontological Social Work*, *46*(2), 37-50.
- Loppie, C. (2007). Learning from the grandmothers: Incorporating Indigenous principles into qualitative research. *Qualitative Health Research*, *17*(2), 276-284.



- Martin, D. H. (2012). Two-eyed seeing: a framework for understanding indigenous and non-indigenous approaches to indigenous health research. *CJNR (Canadian Journal of Nursing Research)*, 44(2), 20-42.
- Martin, P., Kelly, N., Kahana, B., Kahana, E., Willcox, B. J., Willcox, D. C., & Poon, L. W. (2015). Defining successful aging: A tangible or elusive concept?. *The Gerontologist*, 55(1), 14-25.
- Martinson, M., & Berridge, C. (2015). Successful aging and its discontents: A systematic review of the social gerontology literature. *The Gerontologist*, 55(1), 58-69.
- Meadows, J., Le Marechal, K., & Catalan, J. (1998). Mental health problems in older adults with HIV referred to a psychological medicine unit. *AIDS care*, 10(2), 105-112.
- Moore, A. R. (2013). Older People Living with HIV/AIDS (OPLWHA) in Lomé, Togo: Personal Networks and Disclosure of Serostatus. *Ageing International*, 38(3), 218-232.
- Mueller, M. R. (1997). Social barriers to recognizing HIV/AIDS in older adults. *Journal of gerontological nursing*, 23(11), 17-21.
- Nevedal, A., & Sankar, A. (2015). The Significance of Sexuality and Intimacy in the Lives of Older African Americans With HIV/AIDS. *The Gerontologist*, 55(1), 160.
- Nokes, K. M., Holzemer, W. L., Corless, I. B., Bakken, S., Brown, M. A., Powell-Cope, G. M., & Turner, J. (2000). Health-related quality of life in persons younger and older than 50 who are living with HIV/AIDS. *Research on Aging*, 22(3), 290-310.
- Nyirenda, M., Chatterji, S., Falkingham, J., Mutevedzi, P., Hosegood, V., Evandrou, M., & Newell, M. L. (2012). An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC public health*, 12(1), 259.

- Orchi, N., Balzano, R., Scognamiglio, P., Navarra, A., De Carli, G., Elia, P., & on behalf of the SENDIH group. (2008). Ageing with HIV: newly diagnosed older adults in Italy. *Aids Care*, 20(4), 419-425.
- Orel, N., Stelle, C., & Watson, W. (2008, October). Strategies That Work: Addressing HIV/AIDS and Older Adults. *Gerontologist*, 48,74-74.
- Ory, M. G., Zablotsky, D. L., & Crystal, S. (1998). Guest Editorial HIV/AIDS and Aging: Identifying a Prevention Research and Care Agenda. *Research on Aging*, 20(6), 637-652.
- Owen, G., & Catalan, J. (2012). 'We never expected this to happen': narratives of ageing with HIV among gay men living in London, UK. *Culture, health & sexuality*, 14(1), 59-72.
- Poindexter, C. C., & Shippy, R. A. (2010). HIV diagnosis disclosure: Stigma management and stigma resistance. *Journal of Gerontological Social Work*,53(4), 366-381.
- Psaros, C., Barinas, J., Robbins, G. K., Bedoya, C. A., Park, E. R., & Safren, S. A. (2015). Reflections on living with HIV over time: exploring the perspective of HIV-infected women over 50. *Aging & mental health*, 19(2), 121-128.
- Royal Commission on Aboriginal Peoples. (1996). <http://www.aadnc-aandc.gc.ca/eng/1100100014597/1100100014637>
- Reading, C. L., & Wien, F. (2009). *Health inequalities and the social determinants of Aboriginal peoples' health*. Prince George, BC: National Collaborating Centre for Aboriginal Health.
- Robinson, W. A., Petty, M. S., Patton, C., & Kang, H. (2008). Aging with HIV: Historical and intra-community differences in experience of aging with HIV. *Journal of Gay & Lesbian Social Services*, 20(1-2), 111-128.

- Roger, K. S., Mignone, J., & Kirkland, S. (2013). Social aspects of HIV/AIDS and aging: a thematic review. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 32(03), 298-306.
- Rosenfeld, D., Bartlam, B., & Smith, R. D. (2012). Out of the closet and into the trenches: Gay male baby boomers, aging, and HIV/AIDS. *The Gerontologist*, gnr138.
- Rothe, J. P., Ozegovic, D., & Carroll, L. J. (2009). Innovation in qualitative interviews: "Sharing Circles" in a First Nations community. *Injury prevention*, 15(5), 334-340.
- Rowe, J. W., & Kahn, R. L. (2015). Successful aging 2.0: conceptual expansions for the 21st century. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 70(4), 593-596.
- Rowe, J. W., & Kahn, R. L. (1987). Human aging: usual and successful. *Science*, 237(4811), 143-149.
- Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *The gerontologist*, 37(4), 433-440.
- Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). What do we know about older adults and HIV? A review of social and behavioral literature. *AIDS care*, 23(10), 1187-1207.
- Saks, M. & Allsop, J. (2007). *Researching Health: Qualitative, Quantitative, and Mixed Methods*. London: Sage.
- Schable, B., Chu, S. Y., & Diaz, T. (1996). Characteristics of women 50 years of age or older with heterosexually acquired AIDS. *American Journal of Public Health*, 86(11), 1616-1618.

- Schrimshaw, E. W., & Siegel, K. (2003). Perceived barriers to social support from family and friends among older adults with HIV/AIDS. *Journal of Health Psychology, 8*(6), 738-752.
- Shippy, R. A., & Karpiak, S. E. (2005). Perceptions of support among older adults with HIV. *Research on Aging, 27*(3), 290-306.
- Siconolfi, D. E., Halkitis, P. N., Barton, S. C., Kingdon, M. J., Perez-Figueroa, R. E., Arias-Martinez, V., ... & Brennan-Ing, M. (2013). Psychosocial and demographic correlates of drug use in a sample of HIV-positive adults ages 50 and older. *Prevention science, 14*(6), 618-627.
- Siemon, J. S., Blenkhorn, L., Wilkins, S., O'Brien, K. K., & Solomon, P. E. (2013). A grounded theory of social participation among older women living with HIV/Une théorie ancrée pour analyser la participation sociale chez les femmes âgées atteintes du VIH. *Canadian Journal of Occupational Therapy, 80*(4), 241-250.
- Siegel, K., Raveis, V., & Karus, D. (1998). Perceived advantages and disadvantages of age among older HIV-infected adults. *Research on Aging, 20*(6), 686-711.
- Skalski, L. M., Sikkema, K. J., Heckman, T. G., & Meade, C. S. (2013). Coping styles and illicit drug use in older adults with HIV/AIDS. *Psychology of Addictive Behaviors, 27*(4), 1050.
- Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. Zed books.
- Solomon, P., O'Brien, K., Wilkins, S., & Gervais, N. (2014). Aging with HIV and disability: The role of uncertainty. *AIDS care, 26*(2), 240-245.
- Speer, D. C., Kennedy, M., Watson, M., Meah, J., Nichols, J., & Watson, B. (1999). Ethnic, demographic, and social differences among middle and older adults with HIV/AIDS. *AIDS patient care and STDs, 13*(10), 615-624.

- Stewart, S. L. (2008). Promoting Indigenous mental health: Cultural perspectives on healing from Native counsellors in Canada. *International Journal of Health Promotion and Education, 46*(2), 49-56.
- Storholm, E. D., Halkitis, P. N., Kupprat, S. A., Hampton, M. C., Palamar, J. J., Brennan-Ing, M., & Karpiak, S. (2013). HIV-related stigma as a mediator of the relation between multiple-minority status and mental health burden in an aging HIV-positive population. *Journal of HIV/AIDS & Social Services, 12*(1), 9-25.
- Szirony, T. A. (1999). Infection with HIV in the elderly population. *Journal of gerontological nursing, 25*(10), 25-31.
- Truth and Reconciliation Commission of Canada. (2015). Final Report.  
<http://www.trc.ca/websites/trcinstitution/index.php?p=890>
- Vance, D. E. (2006). Spirituality of living and aging with HIV: A pilot study. *Journal of Religion, Spirituality & Aging, 19*(1), 57-74.
- Vance, D. E., Struzick, T. C., & Masten, J. (2008). Hardiness, successful aging, and HIV: Implications for social work. *Journal of gerontological social work, 51*(3-4), 260-283.
- Vance, D. E., Struzick, T., & Childs, G. (2010). Challenges of depression and suicidal ideation associated with aging with HIV/AIDS: implications for social work. *Journal of gerontological social work, 53*(2), 159-175.
- Vance, D. E., & Robinson, F. P. (2004). Reconciling successful aging with HIV: A biopsychosocial overview. *Journal of HIV/AIDS & Social Services, 3*(1), 59-78.
- Walker, R. C. (2008). Aboriginal self-determination and social housing in urban Canada: A story
- Wells, Kathleen. (2011). Narrative Inquiry. Oxford Scholarship Online. doi:  
10.1093/acprof:oso/9780195385793.001.0001

- Wallach, I., & Brotman, S. (2013). Ageing with HIV/AIDS: a scoping study among people aged 50 and over living in Quebec. *Ageing and Society*, 33(07), 1212-1242.
- Waysdorf, S. L. (2002). Aging of the AIDS Epidemic: Emerging Legal and Public Health Issues for Elderly Persons Living with HIV/AIDS, *The Elder LJ*,10, 47.
- Wilson, K., & Rosenberg, M. W. (2002). Exploring the determinants of health for First Nations peoples in Canada: can existing frameworks accommodate traditional activities?. *Social science & medicine*, 55(11), 2017-2031.
- Wooten-Bielski, K. (1999). HIV & AIDS in older adults. *Geriatric Nursing*, 20(5), 268-272.
- Wright, S. D., Drost, M., Caserta, M. S., & Lund, D. A. (1998). Older adults and HIV/AIDS: Implications for educators. *Gerontology & Geriatrics Education*,18(4), 3-21.
- Zablotsky, D. L. (1998). Overlooked, ignored, and forgotten older women at risk for HIV infection and AIDS. *Research on aging*, 20(6), 760-775.
- Zelenetz, P. D., & Epstein, M. E. (1998). HIV in the elderly. *AIDS patient care and STDs*, 12(4), 255-262.

## **Appendix A: Principles of Research Collaboration**

### **Principles of Research Collaboration Between the Canadian Aboriginal AIDS Network And [INSERT NAMES]**

#### **Parties**

This document constitutes Principles for Research Collaboration (PRC) between [INSERT NAMES] (investigators) and the Canadian Aboriginal AIDS Network, a national non-governmental organization dedicated to providing, support and advocacy for Aboriginal People living with and affected by HIV/AIDS regardless of where they reside.

The Canadian Aboriginal AIDS Network will participate as a member of the research team under the terms identified below through [INSERT NAMES].

The above listed individuals constitute the research team. Additional members may join in signing this PRC and participate as members of the research team once all members (listed above) have agreed.

#### **Purpose**

The purpose of this PRC is to establish a set of principles that guide the conduct of the research project, “[INSERT PROJECT TITLE]”. In short, this agreement acknowledges the importance of incorporating cultural values and perspectives into the research process.

#### **Records**

The Principal Investigator (PI) and project coordinator will coordinate all administrative matters relating to the above named research project. The PI or project coordinator will provide each member of the research team with notes of meetings, including decisions made, within a reasonable time frame.

#### **Ethical Considerations**

Ethical codes of conduct for research in Aboriginal communities have been articulated in the *Tri-Council Policy Statement 2 (TCPS 2)*, *Tri-Agency Framework: Responsible Conduct of Research* and also specifically in the *CIHR Guidelines for Research Involving Aboriginal People*. However, each member of the research team collectively shares the responsibility for raising ethical concerns and issues. Ethical dilemmas are resolved on the basis of the research team striving for a significant degree of consensus.

#### **Duration and Amendments**

This PRC will be in effect throughout the entire research process, from the development of research questions through data collection and analysis phases into dissemination of findings. This PRC can be amended upon mutual consent by members of the research team.

## **Principles of Ethical Research with Aboriginal Peoples and Communities**

The research team acknowledges and supports the principles of ethical research with Aboriginal Peoples and Communities as outlined below. This section has been developed based upon the First Nations principles of OCAP™: Ownership, Control, Access and Possession.<sup>1</sup>

- Members of the research team acknowledge and respect the Aboriginal right to self-determination, including the jurisdiction to decide about research in their communities. In doing so, the research process shall be built upon meaningful engagement and reciprocity between the research team and Aboriginal communities. Further, the research team agrees they will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.
- The research team will strive to include meaningful and equal participation from Aboriginal community members. Therefore, the parties agree they will be jointly and equally involved from beginning to end in the research process, from research question formulation, through data collection, analysis and into dissemination of research findings related to the above named project.
- The research team may also strive to demonstrate this support by obtaining and attaching letters of support from Aboriginal community leadership at the local level who may assist as either a member of a research advisory committee or in providing assistance related to the recruitment of participants. Primarily, the task of negotiating letters of support from local Aboriginal communities resides with the Canadian Aboriginal AIDS Network.
- The research team agrees that they will collectively make decisions on research questions, in data collection, interpreting results, in drafting research reports and in dissemination of findings. In other words, the PI will not present a completed research design for approval but involve all other members of the research team in the process.
- The research questions must not only reflect academic interests but ensure that the research is also relevant and beneficial to Aboriginal communities.
- In dissemination strategies to Aboriginal communities, the research team agrees that the language and manner of sharing research will be appropriate.
- The (purpose of) research project will be explained to all stakeholders (participants and Aboriginal community members) in a language that is appropriate to the Aboriginal community. Likewise, the research team will explain potential risks and benefits in a similar manner.

---

<sup>1</sup> The OCAP Principles are Trade Marked by the First Nations Information Governance Centre



- The research team agrees they will not sensationalize problems in Aboriginal communities. Rather, they will strive to present a balanced portrait that also focuses equal attention on positive aspects within the community. As such, the research team understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. The parties agree to review findings in a timely manner (e.g. two months).
- Given that all members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination has occurred, further analyze, publish or present findings resulting from the above mentioned research project unless the entire research team reaches a consensus.
- The PI is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, etc. However, once privacy and confidentiality of participants has been demonstrated, data sets in the form of SPSS, QSR\*N6 (NUD\*IST) or Atlas.ti computer files for example may be shared with all members of the research team. In cases of disagreement over transfer of data sets (as described above), the research team will strive to achieve a significant degree of consensus.
- The research team agrees to provide meaningful and appropriate research capacity-building, as indicated by Aboriginal community participants.
- The research team agrees that Aboriginal communities have the right to follow cultural codes of conduct and community protocols. However, rather than end a research relationship, in situations where Aboriginal community members are in disagreement, the research team will strive to resolve conflict towards achieving a significant degree of consensus.
- The research team agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community elders and other community leadership.

### **Authorship**

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publications based on the findings of the research. The criteria recommend that:

- 1) all authors must make a substantial contribution to the conception, design, analysis, or interpretation of data;
- 2) authors must be involved in writing and revising the manuscript for intellectual content; and
- 3) authors must approve the final draft and be able to defend the published work.

Those who have made other contributions to the work (e.g. data collection without interpretation, etc.) or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship. Further;

- Research project staff may participate as authors provided that they fulfil the criteria outlined above;
- All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research may further analyse, publish or present findings resulting from the above-mentioned research project with the agreement of the Principal Investigator and the other research team members;
- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation;
- A research team member or a partner may chose to include a disclaimer if they do not agree with the content or views presented in a publication.

IN WITNESS WHEREOF, the parties hereto have executed this agreement.

_____	_____
<i>(Date)</i>	<i>(Signature)</i>

_____	_____
<i>(Date)</i>	<i>(Signature)</i>

_____	_____
<i>(Date)</i>	<i>(Signature)</i>

_____	_____
<i>(Date)</i>	<i>(Signature)</i>

## Appendix B: Sharing Circle Guide

### **SHARING CIRCLE INTERVIEW GUIDE**

#### **Indigenous peoples, Aging & HIV/AIDS**

Researcher: Chaneesa Ryan

***[THE COMPLETION OF THE INTRODUCTORY SECTION OF THE SHARING CIRCLE SHOULD TAKE APPROXIMATELY 10-15 MINUTES]***

#### **I) INTRODUCTION AND INSTRUCTIONS:**

Hello, my name is Chaneesa Ryan, I am a Master's student in the department of Health, Aging and Society and I am doing this research for my thesis and I am non-Indigenous. **[Explain a little bit more about myself and my interest in Indigenous health and my research topic].**

Thank you for agreeing to participate in this sharing circle. Just to remind everyone, I'm looking at opinions about your experiences of being an Indigenous person and aging with HIV/AIDS.

***[POINT OUT REFRESHMENTS if available, NAME TAGS if used – people should use their first name or pseudonym only].***

In a minute, we will all introduce ourselves – first names only. But first, I would like to walk you through the consent form that is in front of you.

***[FOR FACILITATOR: REVIEW INFORMED CONSENT FORM AND ANSWER ANY QUESTIONS ABOUT IT. COLLECT SIGNED CONSENT FORMS AND ENSURE THAT PARTICIPANTS HAVE A COPY OF THE LETTER OF INFORMATION TO TAKE WITH THEM (IF APPROPRIATE FOR THE TOPIC AND GROUP).]***

**Confidentiality:** ***[READ ALOUD]*** Before we begin our discussion of your experiences of being Indigenous and aging with HIV/AIDS, I want to spend a few moments **talking about confidentiality** and to go over some basic ground rules for our focus group discussion today:

- Everyone's views are welcomed and important.
- The information which we will collect today will be attributable (*connected or associated*) to you as a group.
- We will not identify quotes or ideas *any one person* of this group. Because of the nature of small communities or groups, it is possible that people could link participants in this room to quotes in the report. This is why we need to talk about confidentiality.
- We *are* assuming that when we learn about one another's views, they remain confidential. In a small community (group) like this, people are identifiable to some degree by their views and opinions.
- Having said this, and having made these requests, you know that we cannot guarantee that the request will be honored by everyone in the room.
- So we are asking you to make only those comments that you would be comfortable making in a public setting; and to hold back making comments that you would not say publicly.

- Anything heard in the room should stay in the room.
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak.
- I may also step in if I feel the conversation is straying off topic.
- You can expect this discussion group to last about roughly 90 minutes.

### **Use of Audio Recorder**

- As you will recall, this focus/discussion group will be recorded to increase accuracy and to reduce the chance of misinterpreting what anyone says.
- All tapes and transcripts will be kept under lock and key by the researcher.
- Names will be removed from transcripts. Participants will have coded numbers attached to their name which only I will know.
- Only I and (*my thesis supervisor and co-researchers for a larger project on Indigenous peoples, aging and HIV/AIDS*) will have access to transcripts (with personal names removed) of this focus group.
- For transcription purposes, I might remind you to say your first name for the first few times you speak so that when I'm transcribing the tape I can get used to recognizing your voice. That will ensure we assign the correct code to each person's answers. I will give you a gentle reminder.
- I'll also ask that when using abbreviations or acronyms, you say the full name at least once to aid transcription.
- We may also use a "flip chart" to write down key points during the focus group and take notes.

***[AT THIS POINT, GROUP MEMBERS CAN QUICKLY INTRODUCE THEMSELVES – remind them that it is 'first names only'.]***

***[HAND OUT ANY MATERIALS (IF APPLICABLE) THAT THE PARTICIPANTS WILL NEED DURING THE FOCUS GROUP INCLUDING PENS OR SCRAP PAPER. GIVE THEM A FEW MINUTES TO READ OVER ANY WRITTEN MATERIAL NOTING THAT THEY CAN MAKE NOTES IN THE MARGINS BEFORE THE DISCUSSION BEGINS.]***

## **II. INTERVIEW**

**Before discussion begins, attention will be turned over to the Elder, who will perform a ceremony, only after explaining its significance and asking the participants if they would like to be involved.**

### **Upon completion,**

Sharing circle discussion begins with the facilitator asking the first question.

*Open up discussion for general responses of participants to each question.*

### **Interview questions:**

1. What does successful aging mean to you?
2. What have you learned – that you can share with others – about living long-term with HIV?
3. What does it mean to be an older Indigenous person living with HIV?
4. What facilitators have allowed you to successfully navigate barriers to health and in turn, live with HIV and age positively?
5. Are there any Indigenous specific interventions that can reduce disability and enhance the overall health of older adults with HIV? Other interventions?
6. Does alternative and traditional medicine play a part in your experience with aging and HIV? Is it important? Has it been a part of your lived experience?

**Wrap-up:**

- Remind participants that “what is said in the room should stay in the room”.
- Thank the participants.

## Appendix C: Recruitment Poster



### PARTICIPANTS NEEDED FOR RESEARCH IN *AGING WITH HIV/AIDS*

We are looking for volunteers to take part in a study of:

The lived experiences of aging Aboriginal peoples affected by HIV/AIDS

This study seeks: to better understand the lived experiences of Aboriginal men and women who are age 50 or over and are living with HIV/AIDS as well as service providers. We are hoping to foster open-ended discussion regarding current needs and hopes with respect to aging with HIV/AIDS from a cultural and gender specific lens. In particular I am hoping to gain a better understanding of what facilitators have allowed you to successfully navigate barriers to health and consequently, age successfully with HIV.

You would be asked to: participate in 1 of 3 open-ended sharing circles for women, men and transgender participants, which will each be held separately.

Participation would involve 1 two-hour session,  
in appreciation of your time, you will receive \$25.

*Refreshments will also be provided.*

Please note that CAAN will not be made aware of who does and does not participate in the sharing circles. Individual's decision to participate or not will have NO EFFECT on your standing with, or the services you receive by CAAN. To help ensure your confidentiality of your participation in this study please contact me (the researcher) directly and not CAAN.

For more information about this study, or to volunteer for this study,  
please contact:  
Chaneesa Ryan  
(905) 536-3060  
[ryancr@mcmaster.ca](mailto:ryancr@mcmaster.ca)

**This study has been reviewed by, and received ethics clearance  
by the McMaster Research Ethics Board.**

**Appendix D: Indigenous Model of Successful Aging**

