**University of Alberta**

# A Narrative Inquiry into the Experiences of sub-Saharan African Immigrants Living with HIV in Alberta, Canada

by

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## Dedication

To

Victorina Manalo dela Cruz and Abelardo C. dela Cruz, my Mom and Dad

Stephen, Daphne dela Cruz and Mateo dela Cruz Yip, my loving family

# Abstract

Current epidemiological data show an increasing number of men and women from sub-Saharan African countries who are living with HIV in Alberta. New cases of HIV between 1999 and 2008 among both men and women in the heterosexual (endemic) risk category have increased. In 2008, one Alberta HIV Clinic estimated that 20% of new HIV-positive clients had come from HIV-endemic countries; this had increased from 1% in 1998. There is little known about the experiences of African immigrants living with HIV in Alberta communities. The purpose of this narrative inquiry was to understand the experiences of sub-Saharan African immigrants living with HIV in Alberta. Clandinin and Connelly's (2000) form of narrative inquiry was the qualitative methodology used for this study. Following the collection of field texts through in-depth conversations and field journal writing, narrative accounts were co-composed with research participants. Three participants' narrative accounts are presented in the dissertation and center on stories of childhood, life before living in Canada, coming to Canada, living in Canada, receiving an HIV diagnosis and living with HIV. A unique researcher-participant relationship allowed for extended collaboration and the development of a close researcher-participant relationship, with relational ethics at the center. Narrative threads that resonated between participant accounts included: stories to live by (narrative forms of identity), including the search for narrative coherence and living in the midst of transition; found and chosen communities; and narrative interlappings. This dissertation concludes with a chapter discussing the personal, social and practical

significance of this study: the phenomenon of narrative inquiry, the social landscapes that shape experience and stories to live by, and new possibilities that nurses may attend to.

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# Chapter 1: Narrative Beginnings

## Prologue

Since engaging with my doctoral work I have changed in multiple ways. I have come to not only understand Clandinin and Connelly's (2000) notion of living in the midst, but also have lived and embraced their notion in this work. Looking across the chapters of this dissertation I can see that I arrived at a profoundly different place than the place where I had started. My understanding of the conceptual and theoretical frameworks which underpinned this work shifted from a focus that aligns well with a critical social perspective and the social determinants of health, to one that forefronts pragmatism and hence experience over time, place and in diverse contexts. Part of this shift was influenced by closely attending and remaining wakeful to relational ethics. Relational ethics required me to attend to my each participant first. There are borderland spaces that are shared between these approaches (Clandinin & Rosiek, 2007), but there are also differences and tensions. Over time I have come to recognize these tensions as different starting places for understanding the experience of living with HIV among immigrants from sub-Saharan Africa, now living in Alberta, Canada. Both offer us different insights. Throughout this dissertation I hope that others will see the shifts that happened for me, shifts that were only possible because of the close relationship with participants, relationships with Lesedi, Rita and Sifa. It was these experiences that shifted me, and that called me to engage with a body of literature previously unfamiliar to me. These experiences of reading unfamiliar texts and engaging with Lesedi, Rita and Sifa opened up a new world for me, one in which I could travel between different theoretical perspectives and one which profoundly changed who I am and have yet to become (Greene, 1993).

## Where (Part) of My Story Began

Thomas King (2003) once wrote that we are all made of stories and that stories are what we really are. I begin this chapter by sharing a story about what brought me to this work and the completion of this dissertation. I start by saying that this is only part of my story. No one comes with one, singular story, but many. I share only one of my stories, my narrative beginnings that are relevant to this study. Our lives are made up of many stories, reflective of our many diverse experiences, and as the Nigerian author Chimamanda Adichie (2009) described, it is important to understand each person's life stories. If we only choose to see a person through a singular story, then we often only understand very little about the person and their life. Chimamanda Adichie's call to attend to multiple stories, stories we all carry in our lives is important; she points to the danger of framing a life through a single story.

In early 2000, I worked closely with people in Alberta to develop and implement HIV prevention and education programs in the community. It was one of the highlights of my career as a public health nurse, using principles of community development and community action, spending time with many people planning, implementing and evaluating HIV prevention programs in the community. I had many conversations with people about the unique experiences they were facing in the community with respect to HIV prevention and education. Spending time with people and communities stimulated my thinking and made me ask many questions about some of these experiences. But there was one particular relationship I had with one Alberta African community that made a lasting impression on me. It was my experience with this community that started my inquiry journey and eventually led me to this study. As a nurse, I've worked with many people from diverse ethnic communities. I have had the chance to hear many stories of migration to Canada and challenges of living as an immigrant in Canada. I am also a second generation immigrant, with parents who migrated to Canada over forty years ago. Throughout my life, I have heard and lived through my family's stories of living in Canada as immigrants.

This study is a part of my personal, practical and professional knowledge landscapes (Clandinin & Connelly, 1995). It is an important part of the relationships I have made with people over the years, working in the area of HIV prevention, education, and support. The purpose of this research was not by chance. It developed over time, influenced by many experiences and conversations with people I've met and worked with in the community and with immigrants who are affected by HIV in Alberta. In 2006, I formally began my journey of inquiry as I embarked on my doctoral work, hoping to delve more deeply into my puzzle about the experiences among sub-Saharan African immigrants living with HIV in Alberta.

The broader story of the HIV illness experience among African[1] immigrants in Alberta is complex. There is a small, but growing body of knowledge that tells us about African immigrants in Alberta who are affected by HIV. This study will contribute to this body of knowledge; it provided an opportunity for African immigrants to tell their stories of experience.

## The Turn to Narrative Inquiry

Narrative inquiry offers a way to explore people's experiences, to understand experiences over time, in place, and in social contexts. It also allows researchers to understand experiences through a collaborative relationship between the researcher and participant (Clandinin & Connelly, 2000). The relationship between the researcher and participant develops over time, in a place or series of places, where social interaction between the researcher and participant facilitates the co-creation of narratives for inquiry (Clandinin & Connelly, 2000). I chose narrative inquiry because of its philosophical underpinnings. Narrative inquiry rests in the interpretive paradigm. Often described as the contrasting paradigm to empiricism, interpretive paradigms are related to the idealist approaches to inquiry (Gortner, 1999; Polifroni & Welch, 1999). The ontology of interpretive paradigms assumes that multiple realities exist and that truths can never be determined as a single truth; truth is not singular, but plural. Further, realities are based on the experiences and greater contextual environments of people. The epistemology of interpretive paradigms is based on the supposition

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[1] For the purpose of this study, "African" will refer to sub-Saharan African countries.

that knowledge is derived from lived experiences, art, and ethics and that observations are made with values (Monti & Tingen, 1999). Using an interpretive paradigm, the researcher is engaged in the research process rather than located as an objective outsider to the process.

In narrative inquiry the researcher and participant collaborate to tell and re-tell, live and re-live stories of experience (Clandinin, 2013). This relationship situates the researcher in a position to work alongside another person and together inquire into experiences. Clandinin and Connelly (2000) discussed the turn to narrative as a way to understand lived and told stories of people's experience. It is a turn from numbers to narratives to understand phenomena. It is also a turn towards a different relationship between the researcher and participant. For example, the relationship is seen as a relational one, one that is embedded in time, place, and a social and personal context (Pinnegar & Daynes, 2007). For these reasons, I chose Clandinin and Connelly's (2000) form of narrative inquiry as methodology, to experience and live the multidimensional, dynamic, temporal, and relational aspects characteristic of the research process. Each narrative inquiry begins with what Clandinin and Connelly (2000) called a narrative beginning, which situates the researcher in the research puzzle. Narrative beginnings also remain central throughout the inquiry as the researcher remains mindful of the continuous unfolding of their own and their participant's lives.

## Locating Myself in Narrative Inquiry

Narrative inquiries are "composed around a particular wonder or research puzzle" (Clandinin & Connelly, 2000, p. 124). My particular research puzzle came from an experience I had while working with a local African community in Alberta in 2003. At that time, a colleague and I worked with the leaders of this community to support their work in developing an HIV prevention and education strategy for their community. Together, we discussed the concerns the community had about their young adults who were engaging in high risk behaviors, and the potential for HIV transmission in their community. We spent over a year together, creating a plan of action to raise community awareness and to increase young people's knowledge about HIV. Towards the end of the project, we heard comments from some of the young people in this community: "there is no HIV in Canada, so I don't worry about it;" "it's ok for me to have sex with a prostitute because there is no HIV in Canada;" "I don't need to wear a condom when I'm with a woman – it is safe here" (Personal Communication, Anonymous Participants, April, 1, 2004). When I sat down with the leaders of the community and learned what the young people were saying, I could not forget the concern they expressed. I also remember my own thoughts and feelings at that moment, including thoughts about the challenges that this community faced in addressing the many misconceptions of HIV. The project eventually ended and over time so too did the relationship I had with this community. But the experiences lingered and left me with more questions: Why did these young people feel and think the way they did about HIV?; How did they think about their own personal risk for HIV transmission?; What were they experiencing in their lives that resulted in them perceiving HIV in this way?; and How did they imagine their future? It was shortly after my work with this community that I knew I wanted to understand where these young people were coming from. I realized that there was a bigger story to be told by this community and their young members. I too wondered about the experience of immigrants living with HIV in Alberta - what shaped these experiences, experiences far away from the country where they were born? How did people continue to compose forward looking stories? What were the transition spaces between geographic places?

## Social Significance and Purpose

As a multi-cultural country of about 33.4 million people, Canada is home to approximately 6.2 million people who were either born outside of Canada, or who immigrated to Canada (Statistics Canada, 2012). Of this population, approximately 5 million people are of visible minority, including approximately 784,000 people belonging to the Black community (Statistics Canada, 2006). People from the Black community continue to face burdens of HIV in Canada (Tharao, Massaquoi, & Teclom, 2006). Canadian epidemiological data suggests an increasing number of HIV infection among people who come from HIV-endemic countries, including sub-Saharan Africa (PHAC, 2011). Estimates from Ontario suggest that approximately 22-59% of HIV-positive persons from HIV-endemic countries contracted the virus after arriving in Canada (Gray, Calzavara, Tharao & Johns, 2008). Alberta is one of four Canadian provinces with the largest number of people who originate from countries where HIV is endemic (PHAC, 2012). The epidemiological term ‘endemic’ refers to regions where there is a high prevalence of HIV infection among the general population and where the incidence of HIV infection is equal to or greater than 1% (PHAC, 2009). The Public Health Agency of Canada (PHAC) maintains a list of countries where HIV is endemic and includes most sub-Saharan African countries (PHAC, 2009).

Tharao and colleagues (2006) reported several factors contributing to the burden of HIV among immigrants in Canada: poverty; cultural and religious stigma related to HIV and AIDS; gender discrimination and gender roles; immigration status; and settlement issues. There are few Canadian studies which explore the storied experiences of HIV among the African immigrant population in Canada. Falconer (2005) reported fifteen studies or reports completed in Canada which are specific to HIV and AIDS and African and/or Caribbean peoples. All have been completed in Eastern Canada and in larger metropolitan centers such as Toronto (Falconer, 2005). To date, there are several studies (Este, Worthington, & Leech, 2009a; Este, Worthington, Leech, & Mazonde, 2009b; Donnelly, Schnee, Worthington, Kovacs Burns, & Lai, 2009) that focus on HIV among Alberta residents of African ancestry. Although there is emerging research in western Canada, there is still little known about immigrants, their storied lives of past, present and future and how these influence the experience of living with HIV.

The Canadian population mosaic is becoming more and more diverse as Canada welcomes about 220,000 to 250,000 immigrants per year (Citizenship and Immigration Canada (CIC), 2008). In 2012, there were 257,887 immigrants welcomed to Canada across all categories of immigration (CIC, 2012). It is important to understand the lives of immigrants in Canada who are living with HIV, and the diverse stories they hold to better understand what influences and shapes the health and social outcomes of immigrants living with HIV.

## Research Puzzle

The research puzzle is described as the particular wonder or phenomenon of the narrative inquiry study and in other research might be termed the research problem or question (Clandinin & Connelly, 2000). Using the phrase "research puzzle" moves away from the notion that research is done to find answers and solutions to a research question or problem. Further, by working with a research puzzle, the researcher remains open to the participant's experience and to the relational unfolding of the inquiry. The research puzzle of this study focuses on the experiences of sub-Saharan African immigrants living with HIV in Alberta.

At the beginning of this chapter, I discussed my narrative beginnings and shared a part of where my own story began in the context of this study. It is a good juncture to describe how the research puzzle came to be. The research puzzle is something that has been developed, shaped and informed by many experiences I've had in the past. Before this study began, I knew only that the experience of sub-Saharan immigrants living with HIV in Alberta was likely to be a complex experience and unique to each individual. However, I did not know the specific experiences of African immigrants living with HIV in Alberta.

As I began to think about the research puzzle, I too was reminded of my own experiences. I am a child of immigrant parents, who came to Canada from the Philippines in search of a ‘better life’. It sounds like a cliché statement, something I heard often from many immigrants. To me, it’s not a cliché; living a better life than what my parents had in their home country is something that I experienced growing up as a child. My siblings and I were constantly reminded by my parents of how lucky we were to be in Canada, to be living in a free society that values equality of all people. I experienced a complex childhood and when I became a young adult, I began to ask a lot of questions of my identity. I experienced much tension living in what felt like two different cultures. That is, I often wondered what it meant to be Canadian and what it meant to be Filipino. These questions of identity seemed to intensify when I began high school. Up until high school, I never really considered myself different than my peers. I don’t believe I even recognized the differences in people’s hair, skin or eye color. I wonder now if I did not recognize these, or if I was able to silence parts of my experiences. It wasn’t until other peers in high school would ask me what I was, that I felt obligated to make visible my stories. It took me a little while to figure out that it was a question of different things – my ethnicity, culture, where I’m from, what I spoke. I was asked because of what I looked like. When I was an adolescent, I didn’t know how to answer the question *‘What are you?’*. After all, I was born in Canada, therefore I must be Canadian; but my parents are from the Philippines and they told my siblings and me that we are Filipinos, so I must not be Canadian; I speak English, but then I also speak Tagalog at home, so what did that make me? All these questions caused me confusion as a young person. Eventually, I found myself saying, “My parents are from the Philippines; I was born in Canada.” I think about this answer now and how easily I seem to have created these categories. I found this statement evolved as I understood more about who I was and what shaped me as a Filipino-Canadian. As a young person, it wasn’t easy trying to find my way through the Canadian culture or society we lived in, when at home we lived as Filipinos. Over time, I have realized that categories leak, that I am neither one nor the other (Lugones, 2010).

When I became an adult, I found myself listening more intently to the stories of experience my parents had as a young immigrant family in Canada. I learned over time that their experience of being immigrants didn’t begin when they arrived in Canada in the early 1970s; I learned that their stories always began back home, in the Philippines. Their stories of experience in Canada seemed to always connect to stories of experience in the Philippines. These stories of experiences intrigued me more and more for several reasons. First, their stories spoke to my own history and past. My parents’ and family’s histories shaped who I am today and who I will continue to become in the future (Greene, 1993). Second, I realized the more I listened to my parents’ stories, the more I felt that I understood them, including the way they parented my siblings and I, and the choices they made for our family. I began to understand my parents and our relationship better. I began to see how my 'stories to live by' (Huber & Clandinin, 2005), a narrative term for identity, shifted over time. Identity, as it is narratively conceptualized is a storied life composition (Huber & Clandinin, 2005). "Stories to live by are shaped in places and lived in places. They live in actions, in relationships with others, in language, including silences, in gaps and vacancies, incontinuities and discontinuities" (Clandinin & Huber, 2002, pp. 161–162).

As I thought about the research puzzle for this study, I began to wonder about the experiences of African immigrants living with HIV and how these experiences shape their stories to live by (Clandinin & Connelly, 2000). I also thought about the experiences I shared at the beginning of this chapter. My experiences with this particular immigrant community left me with many questions, mainly, why did young people feel like they were not at risk for HIV in Canada? I imagine the stories behind this perception. Stories that I imagined did not necessarily begin in Canada for immigrants, but stories that might begin in one's home country, much like my parents. These experiences from an earlier place and time of one's life often influence experiences in the present. Experiences are not only shaped over time, but also in diverse geographic places. Would I hear participants speak to their geographic places and the influences on their stories to live by? What cultural, social, political, and ethical stories would participants tell as they made sense of living with HIV? These questions shaped my wonder about the research puzzle: what are the multiple and complex experiences of African immigrants living with HIV in Alberta?

# Chapter 2: Literature Relevant to this Study

## Literature Review

### Introduction.

I have chosen to include a more traditional literature review as part of this dissertation. While narrative inquirers often integrate the literature throughout the entire dissertation (Clandinin, 2013), I felt that a more traditional literature review would provide me with the necessary context to begin the study. I now realize in retrospect that very little of the published literature inquires into experiences or forefronts relational methodologies that explore HIV illness. This was a significant discovery for me that I will discuss in more detail in Chapter 8. It too is a reminder of how powerful research can be and how the absence of particular methodological approaches can shape practices in significant ways.

A literature review was completed to support the understanding of the broader context of HIV globally and locally. The review provided a context for what is currently known about African immigrants' experiences of living with HIV in Canada and elsewhere. The literature in this chapter adds to the broader context of the research puzzle. To understand what is currently known about immigrants who live in Canada and who are living with HIV, the following data bases were searched: CINAHL, MEDLINE/PubMed, PsychInfo, and Social Policy and Practice. Keywords that were used for this literature review included: immigrant and refugee health, HIV/AIDS in Canada, immigration policy, determinants of health, HIV prevention, and HIV support. Grey literature, including environmental scans, reports, interviews and focus group studies, and annotated bibliographies that were completed by AIDS Services Organizations (ASOs) in Canada, were also retrieved and reviewed.

In this chapter, epidemiological data are summarized, followed by a summary of relevant Canadian studies. Canadian studies are summarized individually rather than in an integrated literature review. This approach was taken because of the small number of studies completed in Canada, as well as differences in each study design. Although each study explored similar topics, they varied in sample (immigrants from African or Caribbean countries, or both; immigrants who were living with HIV, or not living with HIV; service providers; and community leaders and members), sample size, and location (eastern Canada, western Canada, rural or urban). Though each study in Canada was unique, there were several similarities in findings, namely: issues of stigma and confidentiality; cultural factors; settlement and integration factors that impact people's views of HIV illness; and access to support and care services in the community. Finally a section highlighting literature regarding HIV-related stigma[2], African beliefs on health, illness and health care seeking behaviors, and current Canadian immigration policies are discussed in the sections that follow.

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[2] There is no consensus in the literature regarding the use of the terms 'HIV/AIDS stigma', 'HIV/AIDS-related stigma', 'HIV stigma', 'HIV-related stigma', 'AIDS stigma', or 'AIDS-related stigma'. For the purpose of this dissertation, the term 'HIV-related stigma' will be used, congruent with the Interagency Coalition on AIDS and Development (ICAD) and the UNAIDS, the Joint United Nations Programme on HIV/AIDS.

### HIV as a global, national, and local concern.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that about 33.4 million people are living worldwide with HIV (UNAIDS, 2012). The majority of people in the world living with HIV infection are from sub-Saharan Africa. Sub-Saharan Africa accounts for 69% of all people living with HIV worldwide (UNAIDS, 2012). It is estimated that about 1 in every 20 adults are living with HIV in sub-Saharan Africa (UNAIDS, 2012).

The HIV epidemic has also affected many high income countries, including Canada. There are Canadian-born and foreign-born Canadian citizens and permanent residents who are living with HIV in Canada. It is expected that the number of people living with HIV will increase in Canada, due to changing trends in HIV incidence in the general and immigrant populations, as well as global migration patterns and longer survival prospects for persons living with HIV. In the early years of the epidemic, Canadian epidemiological data suggested that HIV was associated primarily with men who have sex with men (MSM) (Public Health Agency of Canada [PHAC], 2005a). However, over the last 20 years, changing trends now show that HIV affects not only MSM, but also women, immigrants, heterosexual couples and in some cases, children. Globalization, mobility of people from nation to nation, improved epidemiological data collection, and immigration policies are all factors that have had impact on HIV trends in Canada.

One of the main limitations of HIV and AIDS surveillance data is that they do not accurately represent the actual number of people infected with HIV (prevalence) or the number of people infected each year (incidence). Current data understate the magnitude of HIV and AIDS in Canada (PHAC, 2011). Estimates can only be drawn from provincial and territorial data due to various factors: different patterns in HIV testing among individuals; differences in reporting systems across provinces and territories; and Canadians' general lack of awareness around HIV testing (PHAC, 2011). However, even with limitations in HIV and AIDS surveillance data in Canada, it is clear that HIV infection is a serious health issue nationally.

In Canada, about 71,300 people are living with HIV, compared to 64,000 people in 2008, showing an 11.4% increase (PHAC, 2011). In 2011, the estimated number of new HIV infections was 3,175 (PHAC, 2011). Surveillance data for 2011 demonstrated significant changing trends in HIV prevalence among several Canadian cohorts. In 1996, women accounted for 10.6% of positive HIV tests, whereas in 2011 women accounted for about one quarter of positive HIV test reports (PHAC, 2011). Men who have sex with men (MSM) continued to account for the largest proportion (46.7%) of positive HIV tests in Canada. However, the heterosexual exposure category also accounted for a significant proportion of positive HIV tests at 32.5%, a growing trend since 2001 (PHAC, 2011). The heterosexual exposure category is divided into two subcategories:

heterosexual-endemic (a person born in a country where HIV is endemic), and heterosexual-non-endemic.

National surveillance data demonstrates that people from HIV-endemic countries are becoming over-represented in national HIV data (PHAC, 2010). It is estimated that the HIV infection rate among people who come from HIV-endemic countries is about nine times higher than other Canadians (PHAC, 2011). This changing trend could be due to a number of factors such as immigration patterns and current immigration policies. Since 2002, there have been several changes to Citizenship and Immigration Canada (CIC) policies which have required mandatory HIV screening for all immigration applicants who require an Immigration Medical Examination (IME). Between January 2002 and December 2011 approximately 5,244 people who underwent an IME tested positive for HIV. In 2011 alone, 476 individuals tested positive for HIV through the IME process, and within this group 56.1% were born in Africa and the Middle East, 29% in the Americas, 11.6% in Asia, and 3.4% in Europe (PHAC, 2011). The Public Health Agency of Canada (2011) reported that 265 of the 476 positive HIV tests were done in Canada and 211 of the 476 tests were done outside of Canada, by designated medical practitioners. The shifting epidemiological trend of HIV in Canada among people who migrate from African countries where HIV is endemic warrants research to learn more about this population.

As of 2011, Canada’s population was estimated at about 33.4 million people (Statistics Canada, 2012). During the first quarter of 2010, more than 70%

of Canada’s increase in population during this time was driven by international migration (Statistics Canada, 2010). Alberta was noted as the province with the fastest growing immigration rate during this period (Statistics Canada, 2010). With a population of approximately 3.7 million people, Alberta’s growth was driven by both its natural increase as well as international and inter-provincial migration. It is estimated that in a three-month period of 2010, 7,300 immigrants came to Alberta (Statistics Canada, 2010). According to Statistics Canada (2006), it is estimated that there are 47,000 Black immigrants in Alberta, including about 35,500 people who were born in Africa.

Since 1998, the Alberta incidence of HIV infection has fluctuated very little, ranging from about 5 to 7 cases of HIV per 100,000 Albertans (Alberta Health and Wellness, 2004). In 2004, there were new 172 cases of HIV (Alberta Health and Wellness, 2004), compared to about 225 new cases of HIV in Alberta in 2008 (Alberta Health Services, 2010). Generally, the risk for HIV infection is growing among the heterosexual population, especially among women. There are also increases of HIV infection among Albertans who come from countries where HIV is endemic (Calgary Health Region, 2005). There are approximately 3,000 people living with HIV in Alberta, including both the number of people registered at both HIV clinics and an estimate of those who are not yet diagnosed (personal communication, S. Houston, April 12, 2011). Recent statistics show an increasing number of new HIV cases in Alberta in the heterosexual (endemic) risk category between 1999 and 2008 (Alberta Health Services, 2010). Further, there is an increasing number of new HIV cases among women from HIV-endemic countries (Alberta Health Services, 2010). In 2010, of the 1,350 known persons living with HIV in Alberta, approximately 33% are non-Canadian born, with the majority coming from Africa; approximately 20% of Alberta's HIV cases are among people who come from African countries (personal communication, J. Gill, September 30, 2010; personal communication, S. Houston, September 30, 2010).

There are two HIV specialty clinics in Alberta which provide treatment and care for those infected with HIV. The two clinics are located in Edmonton and in Calgary, and are funded by the Government of Alberta. There are also community-based support services for people living with HIV or affected by HIV in Alberta. Such services are provided through AIDS Service Organizations (ASOs) in Alberta (Alberta Community Council on HIV, 2010). These community based organizations are located throughout the province, in both urban and rural areas. There are no ASOs in Alberta that specifically reach newcomer immigrants. Rather, services for immigrants living with HIV are integrated into existing mainstream programs and services. This is particularly important to note as mainstream ASOs can make some African immigrants uncomfortable if the focus of programs is primarily for gay men and people who inject drugs (Health Canada, 2000). Although many mainstream ASOs have staff who work with immigrant and refugee clients, there still remain issues about access, privacy and stigma.

**African immigrants living with or affected by HIV: The Canadian and Alberta context.**

Currently, there is a small but growing body of literature that focuses on the experiences of African immigrants and immigrants in Canada, the perception of risk for HIV in Canada, and the experiences of living with HIV in Canada. Much of this work has been done in eastern Canadian cities. While most immigrants and refugees initially enter Canada through places like Montreal, Toronto or Vancouver, many immigrants have recently come directly to or settle in Alberta (Krentz & Gill, 2009). In 2006, about 7% of Alberta's immigrant population came from African countries (Statistics Canada, 2006). Krentz and Gill (2009) noted that there has been an increase in the number of immigrants living with HIV in Alberta. Data from 2007 indicate that about 20% of HIV-positive tests in Alberta were diagnosed among people from HIV-endemic countries (Singh, 2008). The increased incidence of HIV in Alberta among people from HIV-endemic countries brings forth important questions about how people experience HIV in the context of migration and settlement. Currently, there are few studies in Alberta that examine the experiences of African immigrants living with HIV in Alberta. At the outset of this study, the studies in the following paragraphs were reviewed as part of the formal literature review. Because the experience of HIV among African immigrants is strongly shaped by migration history, legal status in a settlement country (Ndirangu & Evans, 2009), and settlement country social contexts and policies (Flowers et al., 2006; Ndirangu &

Evans, 2009), I purposely chose to examine Canadian studies in which participants migrated under Canadian immigration policy. Key findings from several studies completed in eastern Canada, as well as those completed in Alberta have been highlighted in the sections that follow.

Much of the work in eastern Canada has examined the knowledge, attitudes, beliefs towards HIV, and experiences of men or women affected by HIV who come from African and Caribbean communities. A community-based research study completed by Tharao and colleagues (2006) engaged African and Caribbean women in Toronto in discussions about HIV and AIDS. Key factors influencing the transmission of HIV and women's response to HIV and AIDS were identified: socioeconomic status, poverty, and unemployment or underemployment impacted the way women experienced their illness (Tharao et al., 2006). As well, some of the participants discussed their experiences of being an HIV positive immigrant in Canada. Some women reported that being diagnosed during the immigration process was an overwhelming experience during an already stressful time. Participants also expressed concerns and fears that being HIV positive would affect their status or application to become a permanent resident of Canada. For some women, this resulted in fear and avoidance of HIV testing. Women also believed that a positive HIV test would be too overwhelming to cope with while trying to settle and integrate in Canadian society. There were also several women without residency status, or who were undocumented residents in Canada, who reported that they would not attempt to access medical services if they fell ill.

Tharao and colleagues (2006) described factors that affected prevention efforts in these communities: cultural practices and beliefs; power imbalances in relationships between men and women; and stigma related to being infected with HIV. Finally, Tharao and colleagues (2006) reported that although the participants had accurate knowledge about HIV and AIDS, many women perceived HIV to be an issue “back home” (Tharao et al., 2006, p. 7) and many women felt that it wasn’t as much of an issue in Canada. The researchers found that this perception limited women’s ability to directly address issues of HIV and AIDS in Canada.

In another study conducted in Toronto (Gray et al., 2008), researchers explored the behavior, beliefs, attitudes and knowledge of HIV and AIDS among East African people. This was the first large-scale Canadian study that examined HIV and AIDS issues in the context of general health in five East African communities in Toronto. Gray and colleagues (2008) found that knowledge about HIV transmission was high, however there was still inaccurate information about HIV and AIDS in these communities. For example, 72% had accurate information about HIV transmission routes, while 13% of participants did not know if there was a cure for AIDS (Gray et al., 2008). In addition, half of the participants reported not using condoms during sexual intercourse because they felt their partner did not have HIV. The researchers reported that almost 66% of participants who had been tested for HIV in the past were tested as part of the Canadian immigration process. Further, more women than men had received a physician’s recommendation to test for HIV. HIV-related stigma was very prevalent among study participants. Over 50% of participants indicated they would not eat in a restaurant where the cook was HIV positive, 33% indicated that they would not tell others if a family member was HIV positive and nearly 24% indicated that they would not want their child in a classroom with another child who was HIV positive (Gray et al., 2008).

Another study (Lawson et al., 2006) explored the experiences of African and Caribbean people related to HIV-related stigma, fear and discrimination. In this qualitative study, 30 HIV-positive men and women participated in in-depth interviews. The researchers reported a diverse range of factors which increased risk for infection, social isolation and stigma, and decreased access to testing and treatment. For example, many of the participants associated HIV with promiscuity, or with gay men. Further, some participants felt that only those who deviated from their cultural practices and beliefs would most likely contract HIV. Participants described a level of blame towards the individual for contracting HIV, which resulted in the isolation of those who were living with HIV. Participants in this study discussed fears relating to social consequences of being HIV positive. For example, participants living with HIV were concerned about deteriorating physical health, income insecurity, lack of social wellbeing and being rejected or judged by others. This resulted in participants not seeking health or social services that they were in need of (Lawson et al., 2006).

Several studies and environmental scans have been recently completed that focus on HIV in Alberta African communities. One environmental scan examined the HIV and AIDS needs and services environment for immigrants migrating to Alberta from countries where HIV is endemic (Patten, 2005). Patten (2005) found that there was no community-based agency that specifically reached immigrants who were living with HIV in Calgary, Alberta. The author reported many immigration and settlement service providers in Calgary, as well as several ASOs that provided mainstream HIV programs and services. However, when a small sample of immigration and settlement service providers were surveyed about the capacity and need to address HIV among their clients, many stated that clients had never raised HIV as an issue during client contact. One African organization stated that AIDS was not an issue in Canada and therefore it would not be an issue in this particular community or organization. Further, there was a general lack of awareness in the community about how to access free, confidential testing services and treatment and of the services for HIV and AIDS support (Patten, 2005).

Another Alberta study (Este et al., 2009a, 2009b) focused on identifying the HIV service needs of African newcomers, meeting these needs in conjunction with other African newcomer service providers in the community and identifying the most appropriate ways for Calgary ASOs to engage African newcomers in the design and delivery of HIV services. Este and colleagues (2009a) described the context of settlement in this community. They found that newcomers experienced challenges such as adaptation to Canadian culture and practice, employment, changes in gender roles, feelings of social isolation, intergenerational conflict within family, and racism during settlement in a new society (Este et al., 2009a). Este and colleagues (2009a, 2009b) also identified several HIV risk factors within the African newcomer community in Calgary: denial, cultural norms, lack of awareness of HIV infection, low perception of risk for HIV infection, and inconsistent use of condoms. What was striking about these findings was the perception of lower HIV risk in Canada, and that HIV was not perceived as acutely as it was in their home countries. These findings resonate with the perceptions of African immigrants living in eastern Canada.

Este and colleagues (2009a; 2009b) also found several other factors that would not only increase risk of infection but also influence health service and ASO utilization. For example, participants discussed the social stigma related to HIV as a barrier to service utilization. Social stigma was described by participants from two perspectives: stigma as experienced by community members; and stigmatizing actions by health care professionals. Several participants discussed the fear of being seen by another member of the community if they were to access information or services. Participants shared fears related to discrimination and racism from health professionals in Canada (Este et al., 2009a, 2009b). Finally, health seeking behaviors among immigrants were different from those of mainstream Canadians (Este et al., 2009a, 2009b). Several participants shared that the health care system in Africa was very different than in Canada. In Africa, quite often there were no family doctors available, no insurance, and no drug plans. Participants also stated that they would not seek medical care for routine check-ups, unless they were very ill (Este et al., 2009a).

In another Alberta study, Donnelly and colleagues (2009) interviewed African and Caribbean immigrants and health providers in rural Alberta to examine contextual factors affecting HIV illness treatment and prevention. Stigma related to HIV was a significant issue in the community. Participants discussed issues around HIV disclosure to family and friends, feelings of shame, and mistrust. It was clear that stigma, fear and shame related to HIV and AIDS was a major barrier to overcome (Donnelly et al., 2009). Further, most of the participants felt that they would not tell anyone outside of their family that they were HIV positive. Donnelly and colleagues (2009) also reported barriers to accessing the health care system including inadequate transportation, insufficient knowledge of the Canadian health care system, and lack of trust between health care providers and community members. Cultural and social factors influencing the transmission of HIV were also identified. For example, relationships and gender dynamics between men and women were important factors influencing condom use.

Though many of the studies completed in Canada have focused on the African and Caribbean communities in Canada, this study focused only on immigrants from sub-Saharan African countries who were living with HIV in Alberta. Further, some Canadian studies focused on Black communities. In this study, people who were not Black were not excluded from participation.

#### Stigma, confidentiality, and HIV.

Living with HIV may result in profound stigma (Mill et al., 2009). It is also a complex issue because of the duality of stigma. Stigma can refer to personal feelings that people feel towards people living with HIV or it can refer to the person living with HIV or AIDS (PLWHA) and their perception of how others feel about them (Visser, Kershaw, Makin & Forsyth, 2008). Stigma has been defined as an undesirable attribute that an individual has, which affects the person's status in society (Goffman, 1963). It has also been defined as a "powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons" (Alonzo & Reynolds, 1995, p. 304).

Stigma impacts PLWHAs in several ways. For example, stigma can influence health and health seeking behaviors, which has implications for PLWHAs who are being treated for HIV illness. Dlamini and colleagues (2009) found that African PLWHAs, who reported higher levels of perceived stigma, also reported more frequently missed doses of antiretroviral (ARV) medications. People living with HIV may also be hesitant or unwilling to access health services due to fear of labeling (Chesney & Smith, 1999; Herek & Captanio, 1999; Rudy et al., 2005). The experience of stigma and living with HIV as well as the physical, emotional and social effects of HIV-related stigma among Africans have been documented frequently in the literature (Chiu et al., 2008; Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008; Dlamini et al., 2007; Dlamini et al., 2009; Gilbert & Walker, 2010; Greeff & Phetlhu, 2007; Greeff et al., 2010; Hamra, Ross, Orrs, & D'Agostino, 2006; Israel Ballard et al., 2006; Maughan-Brown, 2010; Muyinda, Seely, Pickering, & Barton, 1997). Stigmatization towards PLWHAs or stigma experienced by PLWHAs is important to understand as it has been shown to be a barrier to effective HIV prevention and care (Campbell, Foulis, Maimane, & Sibiya, 2005).

Uys and colleagues (2009a; 2009b) studied stigma longitudinally in African countries. They found that interventions can reduce stigma, but also found that stigma never diminishes completely over time (Uys et al., 2009a). Stigma is an important contextual factor to understand while uncovering the storied lives of African immigrant men and women who are living with HIV. HIV-related stigma is not likely to disappear after migration. In addition, stigma may be intensified due to the concept of layered stigma (Mill et al., 2009). Layered stigma refers to individuals who are already marginalized in society and who experience other forms of stigma such as HIV-related stigma (Bunting, 1996; Canadian HIV/AIDS Legal Network, 2004; Chesney & Smith, 1999; Donnelly et al., 2009; Duffy, 2005; Herdt, 2001; Reidpath & Chan, 2005). Although research about layered stigma among persons living with HIV has focused on marginalized populations such as women or men who have sex with men, there are few Canadian studies specifically examining layered stigma among immigrants.

Tharao and colleagues (2006) found that the experience of stigma related to HIV or AIDS keeps African and Caribbean women from accessing HIV services. Further, fear of disclosure of HIV status was related to fear of losing immigration status, or having influence on immigration application processes (Anderson & Doyal, 2004; Tharao et al., 2006). Stigma is also related to delays in seeking HIV testing (Mitra, Jacobsen, O'Connor, Pottie, & Tugwell, 2006). In this sense, it is critical to understand the experience of layered stigma among immigrant men and women who come to Canada. Stigma may be related to HIV positive status, immigration status, or aspects of their acculturation (language barriers, decline in socioeconomic status, unemployment, etc.) that may concurrently influence the experience of living with HIV in a new country. Implications of perceived and real stigma include delayed access to testing and treatment as well as access to social support from friends, family, and the social services sector (i.e., ASOs) (Anderson & Doyal, 2004; Ndirangu & Evans, 2009).

Closely related to the issue of stigma are concerns about confidentiality and privacy. Several studies (Anderson & Doyal, 2004; Ndirangu & Evans, 2009) found significant concern and worry among people living with HIV related to the disclosure of their HIV positive status. Fear that family, friends, and the local community will find out about their HIV positive status is common among African migrants (Anderson & Doyal, 2004; Ndirangu & Evans, 2009). Ghanaian women often kept their HIV positive status secret in order to avoid stigma and discrimination (Mill, 2001). This too has implications for testing, accessing medical care, treatment, and social support services from community-based agencies.

#### African beliefs on health, illness, HIV, and health care seeking behavior.

Understanding people's explanations for health, illness, and health care seeking behavior are critical not only for effective public health strategies, but also to understand people's experience of health and health-seeking behaviors. Though culture, language, and beliefs differ between and within African countries, there are similarities in terms of traditional beliefs towards health, illness, and health-seeking behavior (Golooba-Mutebi & Tollman, 2007; Liddell, Barrett, & Bydawell, 2006; Mill, 2001; Mshana et al., 2006). In this section, I highlight several aspects of African beliefs about health, illness, and health care seeking behavior that provide important context to understanding the experiences of African immigrants living with HIV in Canada. For example, in sub-Saharan Africa beliefs related to bewitchment, violation of taboos, and spirituality are often linked to illness (Golooba-Mutebi & Tollman, 2007; Mill, 2001). In South Africa HIV-illness among some villagers was believed to be a result of bewitchment (Golooba-Mutebi & Tollman, 2007; Mshana et al., 2006). In Ghana, some women believed that HIV was associated with living a 'basabasa' life, which was associated with improper behavior such as promiscuity or extramarital affairs (Mill, 2001). Traditional knowledge and beliefs shape people's understandings of their social and physical world and come from generations of folk wisdom and experiences that help explain past, current, and future events (Liddel et al., 2006). Early research on the causes of illness in Africa has differentiated naturalistic from personalistic beliefs. As Foster (1976) described:

> A personalistic medical system is one in which disease is explained due to the active, purposeful intervention of an agent, who may be human (a witch or sorcerer), nonhuman (a ghost, an ancestor, an evil spirit) or supernatural (a deity or other very powerful being) . . . Naturalistic systems explain illness in impersonal, systemic terms; Disease is thought to stem from such natural forces or conditions as cold, heat, winds, dampness, and above all, by an upset in the balance of the basic bodily elements. (p.775)

Recognizing the complexity of HIV illness, the experience of HIV illness among African communities is further influenced by deeply rooted complex cultural and social processes (Liddell et al., 2006). Researchers in African countries have found various beliefs about the cause or etiology of HIV illness. For example, while many Africans are aware of the sexual transmission of the HIV virus, there is still widespread belief that HIV is caused by evil spirits, travel, promiscuity, or other supernatural explanations, including the work of God or ancestral spirits (Golooba-Mutebi & Tollman, 2007; Liddell et al., 2006; Mill, 2001; Mshana et al., 2006).

Health care seeking behaviors among Africans are varied and dependent on many factors such as culture, socioeconomic status, gender, marital status, religious and spiritual beliefs, belief of traditional health practices, and availability of health care services, whether traditional or non-traditional (Barimah & Teijlingen, 2008; Homsy, 1999; Homsy et al., 2004; Meyer-Weitz, Reddy, Van Den Borne, Kok, & Pietersen, 2000; Moses et al., 1994; Schellenberg et al., 2003). Many Africans will often first seek traditional treatments, depending on their view of their illness and cause of illness, but may sometimes seek biomedical treatments, if available and affordable (Golooba-Mutebi & Tollman, 2007; Mshana et al., 2006). Traditional medicine in Africa is as diverse as the cultures of the African continent (Homsy, 1999). It is beyond the scope of this chapter to discuss the diverse factors that influence health care seeking behaviors among people from African countries. However it is important to acknowledge the complex factors surrounding health seeking behaviors and how these factors may shape one's HIV illness experience. Understanding people's beliefs about health, illness, and the causes of HIV are important factors to consider in exploring the experience of people from Africa living with HIV in Canada. Prevention, care and support interventions are more likely to succeed when traditional beliefs of health and illness are considered (Caprara, 1998; Golooba-Mutebi & Tollman, 2007; Mshana et al., 2006). Understanding a person's experiences and views of traditional or non-traditional health care use provides important context to one's health and illness experience.

#### Migration and health in the Canadian context.

As a population, immigrants do not generally experience a disproportionate burden of illness, lower than average life expectancy, or compromised quality of life (Beiser, 2005; Lassetter & Callister, 2009). Current Canadian immigration policy selects immigrants on the basis of attributes such as education level and job skills. Further, medical screening also ensures that immigrants in Canada are healthy and not a potential danger or burden to the Canadian health care system. However, there has been much research concerning the health of immigrants in Canada, all of which has produced diverse findings (Beiser, 2005). Three paradigms have traditionally framed immigrant health research: the sick immigrant paradigm; the healthy immigrant paradigm; and the interaction paradigm (Beiser, 2005).

The sick immigrant paradigm is often linked to historical Canadian immigration policies. Until about the mid-20th century, Canadian immigration policy was based on the idea that immigrants came with disease and illness and that the Canadian public had to be protected from newcomers in Canada (Beiser, 2005). There was a time when immigrants in Canada were seen as those who did not come from the “right” place: non-western, Asian or southern European immigrants who came to Canada to provide inexpensive labor for Canada’s railways, mining industry, and agricultural work (Beiser, 2005, p. S31). In fact, quarantine islands were created in eastern Canada to keep immigrants who were screened as carriers of infectious disease or other illnesses away from the

Canadian public (personal communication, R. Vineberg, January 20, 2010). Current immigration policy is still partly reflective of the sick immigrant paradigm. Immigrant applicants who are assessed as potentially dangerous to the Canadian public or public health, or those who could potentially burden the Canadian health and social services system are denied entry to Canada, with the exception of refugee applicants and applicants who are reuniting with family. Further, those who demonstrate active illness (e. g., TB or malaria) and who are permitted to enter Canada are followed by provincial surveillance programs for further monitoring and treatment (Beiser, 2005).

The healthy immigrant paradigm proposes that immigrants enter Canada as generally healthy individuals, but that the health of immigrants declines over time. Analysis of Canada's National Population Health Survey (NPHS) data demonstrates that immigrants who have been in Canada for 10 years or less have fewer chronic illnesses and less disability than native-born Canadians (Ali, McDermott, & Gravel, 2004; Chen, Wilkens & Ng, 1996; Newbold & Danforth, 2003). However, after 10 years, immigrant population health patterns and native-born Canadian health patterns become similar (Ali et al., 2004; Chen et al., 1996; Newbold & Danforth, 2003). Findings from a recent Alberta study (Maximova & Krahn, 2010) were consistent with the healthy immigrant paradigm. Beiser (2005) discussed two possible reasons for the gradual decline of health among healthy immigrants. The concept of convergence suggests that the healthy immigrant's exposure to the physical, social, and cultural environments of the settlement country triggers a trajectory in which health patterns of the immigrant merges with the health patterns of the general population. Beiser (2005) described convergence as both a passive and active process. For example, it could be a result of the immigrant's genetic predisposition to certain health conditions, or exposures to similar environments in their native countries. It can also be a result of more active processes such as adaptation of the settlement country's culture and practices including smoking, alcohol use, and intake of junk foods (Frisbie, Youngtae, & Hummer, 2001; Hazuda, Haffner, Stern, & Eifler, 1988). The second theory of the healthy immigrant paradigm is related to resettlement stress. The resettlement stress paradigm occurs when immigrants' health declines more than the population of the settlement country, as a result of the resettlement experience (Jolly, Pais, & Rihal, 1996; Newbold & Danforth, 2003). According to this paradigm, stressors and experiences related to resettlement, such as unemployment, poverty, or lack of health services, can have negative health impacts on the immigrant (Beiser, 2005).

The third paradigm to explain immigrant health is called the interaction paradigm (Beiser, 2005), which postulates that health outcomes are influenced by immigrant characteristics, pre- and post- migration experiences, and acculturation strategies adopted by immigrants in their settlement country. Compared to the first two models, the interaction model is a more comprehensive model of immigrant health. This paradigm suggests that a broader range of factors must be considered when exploring what makes immigrants well and healthy in their new country. Immigrants come from different countries; some come from politically stable countries, while others come from war-torn countries. In the case of the latter, immigrants who experience stressors such as political instability and war in their countries of origin will likely have different physical and mental health outcomes than those who come from stable countries (Anderson & Doyal, 2004; Maximova & Krahn, 2010). Immigrants in Canada also differ in their entry class category (refugee applicant, reunification applicant, etc.). For example, some immigrants who are entering as refugees in Canada may have significantly different life experiences and stressors related to living in a refugee camp, than applicants who have not experienced life in a refugee camp. Some immigrants may also be more predisposed to certain illnesses than other immigrants, as in the case of immigrants coming from countries where tuberculosis or other infectious diseases are common. Finally, poverty and unemployment, which have been described as universal determinants of health (World Health Organization [WHO], 2010) may result in negative health outcomes among immigrants during their settlement experience (Lassetter & Callister, 2009; Maximova & Krahn, 2010; Meadows, Thurston, & Melton, 2001; Zunzunegui, Forster, Gauvin, Raynault, & Willms, 2006).

Understanding the broader determinants that may influence the health of immigrants is essential to understanding the health experiences of immigrants in Canada. Rather than analyzing only the health or illness of immigrants in Canada at the time of arrival, it is critical to understand the broader factors and determinants that influence the lives of immigrants. Particular attention needs to be made to pre-migration factors that affect immigrant's health, as well as their post-migration experiences that could also affect immigrants' health and life outcomes. Pre-migration factors and post-migration factors such as poverty, unemployment or underemployment, stable housing, acculturation strategies, social networks, and access to health services are all factors that affect the health and wellbeing of immigrants.

### Current Canadian immigration policy.

Immigration status in Canada may influence access to and utilization of health and social services. Under the current Canadian Immigration and Refugee Protection Act (IRPA), there are two categories of foreign nationals who seek entry to Canada (Minister of Justice, 2010a). First, there are permanent resident applicants who seek to enter and remain in Canada. Permanent resident applicants (Citizenship and Immigration Canada, 2012) include[3]: those who wish to reunite with family members who are Canadian citizens or permanent residents; those who fall under the economic immigration category; and those who are refugees under the United Nations Convention Relating to the Status of Refugees (Minister of Justice, 2010a, 2010b). Second, foreign nationals who seek to enter Canada as temporary residents[4] include those who are tourists, visiting family, attending conferences or meetings, attending educational institutions as

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[3] The reader must be aware that Canadian immigration categories may change from time to time and is therefore referred to Citizenship and Immigration Canada for the most recent information and description of immigration categories.

[4] Ibid.

students, or working temporarily in Canada. In order to meet the health requirements prior to entering Canada, immigrants must undergo an International Medical Examination (IME) depending on their application type (Citizenship and Immigration Canada, 2011). Generally, all permanent resident applicants and refugee applicants must undergo an IME, and several types of temporary resident applicants must also undergo an IME. Among other medical tests, a mandatory HIV serologic test is part of the IME. The main purpose of the IME is to determine whether or not the applicant would potentially be a danger to public health and safety; or would reasonably expect to cause excessive demand on Canadian health or social services (Citizenship and Immigration Canada, 2011). If an IME demonstrates that an applicant could potentially pose a danger to the health and safety of Canadians, they are inadmissible (Citizenship and Immigration Canada, 2011). An applicant is also inadmissible if they are predicted to place excessive burden on health and social services. Applicants who are refugees, protected persons, or who are part of the family sponsorship category are exempt from this policy and cannot be inadmissible on these grounds (Citizenship and Immigration Canada, 2013). In this case, the IME serves to provide baseline medical information. Mandatory HIV testing for all immigration applicants age 15 years or older has been in place since January 2002 (PHAC, 2005b).

Examining current Canadian immigration policy was an important consideration for this study, providing critical context to the lives of people who participated in this study. For some immigrant applicants, HIV diagnosis may be established during the Immigration Medical Examination (IME) process. This may impact their illness trajectory as they enter a new country. For others, the IME process may result in a negative HIV serologic test. However, transmission and infection may occur months later in the new host country. These considerations must also be understood when exploring the experiences of immigrants who are living with HIV as it provides important context to living day to day with HIV illness. Krentz and Gill (2009) outlined unique challenges that HIV-infected immigrants and refugees face and present to the health services sector. It is important to understand the various contextual factors, including social and biological, that HIV-infected or affected immigrants bring upon arrival to Canada (Krentz & Gill, 2009). Sub-Saharan African immigrants who are HIV positive, and who migrate and settle in Canada are faced with extraordinary challenges in coping with their illness and with settlement and integration experiences (Donnelly et al., 2009; Tharao et al., 2006). For example, individuals may fear that their HIV status may compromise their immigration status or affect their settlement in their new country.

It is important to explore and understand the pre-migration, migration, and settlement experiences of immigrants. Such experiences provide important information when reaching and engaging immigrants in the community. Further, it is important to understand the experience of living with HIV in a new society, within the context of everyday living. The challenges of settlement and integration could influence the way newcomers engage with the community, as well as access health and social services. Challenges of settlement and integration have been well documented in the literature and it is known that these challenges influence immigrants' experiences of acculturation (Berry, 2007; Phinney, Berry, Vedder & Liebkind, 2006; Phinney & Vedder, 2006; Phinney & Ong, 2007; Sam, Vedder, Ward & Horenczyk, 2006; Vedder, Van de Vijver & Liebkind, 2006).

## Theoretical Frameworks

### Introduction.

In this section, I describe three frameworks or paradigms that were important to the literature review: population health promotion model, bi-dimensional model of acculturation, and cultural safety. Very early in this study, three frameworks shaped my thinking about HIV illness, migration and health among immigrants. These frameworks became a way to help me begin to see people big and not small (Greene, 1995), before I met each of the study participants. That is, the frameworks provided me with a contextual landscape that I could reflect on. This landscape was not to provide me with a preconceived notion of each participant's experience. Rather, each framework provided me an opportunity to think about what might be relevant to each participant's experience of HIV illness, migration, acculturation and settlement. This section highlights each framework that guided my thinking at the outset of this study. In Chapters 7 and 8, I explore how my thinking has shifted with respect to understanding HIV illness experience.

### Population health promotion model.

The theoretical tenets of the population health promotion model (PHPM) define health and wellness from a holistic perspective, integrating many factors that determine people's health (PHAC, 2001). The PHP approach recognizes that broad, contextual, social and environmental factors determine health and influence people's experiences of health and illness. The experience of HIV illness from the perspective of access to health services, medications and responses to medical treatment is only one aspect of the illness experience. Considering the broader contextual and social factors that influence the overall experience of illness is also important. HIV is well documented as being a complex illness and transmission is often a result of multiple factors (Chiu et al., 2008; Cloete, Simbaya, Kalichman, Strebel, & Henda, 2008; Dlamini et al., 2007, 2009; Donnelly et al., 2009; Este et al., 2009a, 2009b; Gilbert & Walker, 2010; Greeff & Phetlhu, 2007; Greeff et al., 2010; Hamra et al., 2006; Israel Ballard et al., 2006; Lawson et al., 2006, Maughan-Brown, 2010; Mill et al., 2009; Mitra et al., 2006; Muyinda et al., 1997; Tharao et al., 2006; Uys et al., 2009a; 2009b). Factors that determine and influence HIV infection and illness include social, political, cultural, gender, socioeconomic, and environmental factors. It is true that HIV infection can be explained in relatively simple terms of person to person transmission of the virus. However, the population health promotion model accounts for the many factors that influence HIV transmission, illness, and treatment.

Within the population health promotion model, the relationship between migration and wellness is seen as an interactive process influenced by temporal and local variables (Gushulak & MacPherson, 2006). Consideration of temporal and other factors are central to understanding experience. Health issues of immigrants should no longer be seen from the perspective of identifying and controlling diseases at the Canadian border. Rather, researchers and practitioners must be aware of the factors that contribute to the health of immigrants upon arrival in Canada, as well as the determinants that influence the health of immigrants during migration and integration into their new host country. Gushulak and MacPherson (2006) argued that a population health promotion approach addresses the health of migrants through broader, more comprehensive means. Examining reasons why people migrate from one country to another, as well as the long term impacts of migration in relation to the different determinants of health and health outcomes of immigrants, are important to understand the experiences and health of immigrants. Through a broader approach to immigrant health, appropriate and meaningful strategies can be developed to address the health of immigrants in Canada.

### *The social determinants of health.*

The social determinants of health are those that are specific to the living conditions of people that either promote health and wellness or cause illness (Mikkonen & Raphael, 2010). They are the conditions in which people grow, live, work and age (World Health Organization, 2010). The social determinants include things such as income, employment, housing, gender, race, and social environments of people. Recognizing the social determinants of health is critical to understanding the day to day experiences of African immigrants living with HIV in Alberta. Many immigrants come to Canada and experience underemployment (Meadows et al., 2001), deskilling in employment (Meadows et al., 2001), unstable housing conditions (Zunzunegui et al., 2006) and lower income levels (Lassetter & Callister, 2009; Zunzunegui et al., 2006). Such factors may have a powerful impact on health and health equity (WHO, 2010). HIV illness cannot be understood only through a singular, biomedical perspective. The social determinants of health facilitate a deeper understanding of how culture, society, and socialization interact.

### Bi-Dimensional model of acculturation.

‘Culturalist discourses’ often relate to the complex practices and ideologies that use popularized or stereotypical representations of culture and are used to understand differences about various groups of people (Browne et al., 2009). Narrow conceptualizations of culture are based on the belief that culture is something fixed and static, and comprises beliefs, values, behaviors, religious practices, and customs inherent to a group of people (Browne et al., 2009). However, as Browne and colleagues (2009) have argued, culture ought to be conceptualized in a broader sense as a much more complex concept not bound within languages, beliefs, and customs alone. Rather, culture is embedded in fields of power relations, social forces such as economics, politics, and historical patterns of oppression and colonization, and is something that is constantly being negotiated within one's own environment (Kirkham et al., 2002). For this study, the broader conceptualization of culture was used to acknowledge that culture is a complex concept, not bounded by languages, customs, or beliefs. Culture and cultural systems are constantly shifting and adapting across spaces of time and place (Kirkham et al., 2002). Bhabha (1994) described culture within a 'third space' and Bhabha (1995) suggested that cultures are never unitary or simply dualistic in relation to 'self' and the 'other'. Further, Bhabha (1995) described the need to focus on the multiple subjective positions, social experiences, and cultural identities that are negotiated in the construction and reconstruction of culture.

The bi-dimensional model of acculturation (Berry & Sam, 1997) also informed my understanding of the influence of migration, acculturation, and cultural identity formation. This model of acculturation asserts that immigrants will experience acculturation differently from one another. Acculturation experiences have been shown to impact the health of immigrants, depending on the strategies used by immigrants to acculturate into their new society (Thurston, Meadows, Este & Eisner, 2006). Further, acculturation accounts for the impact of various determinants of health including culture, physical and social environments, employment, income and social status, and coping skills.

Compared to the one-dimensional acculturation model, whereby immigrants are expected to assimilate completely to their new culture (Gordon, 1964 as cited in Van de Vijver & Phalet, 2004), the bi-dimensional model of acculturation proposes that immigrants will experience acculturation in various ways. The model proposes that the end goal of acculturation is not to assimilate to the new host culture, but rather to integrate into the new host culture. Canadian policies and the Immigration and Refugee Protection Act (IRPA) are reflective of a bi-dimensional approach to acculturation in society, where integration is encouraged among new migrants in Canada (Minister of Justice, 2010a). According to the bi-dimensional model of acculturation, rather than striving to integrate fully into mainstream society (unilateral acculturation or assimilation), the migrant may instead focus on two main aspects of acculturation: adaptation to the new society and cultural maintenance of one's native culture (Berry, 2005; Berry & Sam, 1997). Within this model, the acculturation process would follow one of four paths: integration, assimilation, separation/segregation, or marginalization (Phinney et al., 2006). Integration is the process of the migrant establishing good relations with the host culture, while maintaining good relationships with the migrant's culture of origin. In the psychology literature, integration has also been described as cultural shifting between two cultures, or the formation of a bicultural identity (Benet-Martinez, Leu, Lee, & Morris, 2002). Assimilation is the process of the migrant establishing good relations with the host culture, while not maintaining good relationships with the migrant's culture of origin. Separation/Segregation is the process of the migrants maintaining good relationships with the migrant's culture of origin, while not establishing good relations with the host culture. Marginalization refers to poor relationships with both the migrant's culture of origin and the host culture.

For immigrants, the individual and their culture are central to ethnic identity formation during acculturation (Phinney & Ong, 2007). When people leave their culture of origin and settle in another, they are faced with questions regarding who they are and who they will become in their new host country (Phinney & Ong, 2007). The process of acculturation therefore not only describes the different pathways that people take during the acculturation process, but it also helps researchers understand the development of the ethnic identity of an individual. One's ethnic identity or the sense of belonging to one's culture of origin is a key factor in the way one responds to the host country (Phinney & Ong, 2007). The development of ethnic identity after migration is a complex process. It refers to one's sense of belonging to one's ethnic or cultural group and is recognized as a complex and multidimensional construct. Researchers have recognized the variation and ambiguity in defining and measuring ethnic identity. However, the term ethnic identity has been used to describe one's overall attitudes, knowledge, feelings and behaviors related to one's ethnicity (Phinney, 1990); one's sense of ethnic self that develops over time (Phinney, 1993); the saliency of one's ethnic self across different contexts (Yip & Fuligni, 2002); and individual differences in the strength of ethnic group affiliation (French, Seidman, Allen, & Aber, 2006).

The process and experience of acculturation and cultural identity is complex. For the purpose of this study, understanding such processes informed my thinking about the social, economic, political, and cultural positions of immigrants within their new host country, and the importance of these positions in understanding the experience of immigrants in Canadian society (Thurston et al., 2006). For example, loss in socioeconomic status in the new host country as a result of underemployment, reduced income levels, and deskilling have been documented in the literature and associated with poor physical and mental health among immigrants (Asanin & Wilson, 2008; Bauder, 2003; Matuk, 1996). Also, researchers have found that poor working conditions, language barriers, and decreased social networks in the new host country may also contribute to poorer health among immigrants (Anderson, 1987; Chen et al., 1996; Elliott & Gillie, 1998; Hanna, 1998; Saldov, 1991; Wozniak, 2001). Finally, the process of immigration itself has shown to be a determinant of immigrants' health (Thurston et al., 2006). Thurston and colleagues (2006) found that some immigrants quickly adapted to their new surroundings by using strategies such as expanding their social networks within and beyond their own ethno-cultural community. Others felt like outsiders in their new host country for years (Thurston et al., 2006).

It is important to note that I have only discussed the issue of ethnic identity formation during acculturation and have not included more complex discussions on other various identity formations that occur during one's life experiences. For example, the formation of other identities such as parent, spouse, occupation, and so forth have not been discussed here, as they are beyond the scope of this study. Other identity formations will have impact on the overall acculturation experience and the experience of identity formation.

### Cultural safety.

Cultural safety is a concept in nursing practice and research that refers to how nurses care for and relate to people of different ethnicities (Polaschek, 1998; Ramsden & Spoonley, 1994). The concept was first identified in New Zealand by a group of Maori nurses in order to analyze nursing practice from the perspective of the indigenous minority of the country (Polaschek, 1998; Ramsden & Spoonley, 1994). Culturally unsafe nursing practice includes any actions which diminish, demean, or disempower the cultural identity and well-being of another individual (Polaschek, 1998). Ogilvie, Burgess-Pinto and Caufield (2008) suggested that researchers who wish to conduct culturally safe research in newcomer communities must first understand differences in immigration status. This will facilitate a better understanding of pre-migration and migration experiences, as well as a participant's sense of security in relation to living and thriving in the host country (Ogilvie et al., 2008). Further, recognition and reflection of the power imbalances, institutional discrimination, and the nature of interpersonal relationships among people identified as the native-born or the immigrant is central to the concept of cultural safety (Ogilvie et al., 2008). Several authors have suggested that cultural safety is a central component of high quality nursing practice in culturally diverse countries such as Canada (Anderson et al., 2003; Dion Stout & Downey, 2006; Johnstone & Kanitsaki, 2007; Williams, 1999), and that achieving it should be an ethical standard for all nurses (Polaschek, 1998).

The concept of cultural safety warrants critical reflection on the power relations that underpin constructions of culture (Kirkham et al., 2002). For example, power differentials, socioeconomic status, political contexts, and histories of colonization need to be considered when examining cultures of people. Culture needs to be considered beyond what Kirkham and colleagues (2002) have described as 'essentialism'. We must avoid placing people into groups and immutable categories, and acknowledge the dynamic and shifting nature of people's identities which intersect with people's ethnicity, gender, religion, and other cultural configurations (Kirkham et al., 2002). In order to counter essentialism, Kirkham and colleagues (2002) proposed negotiation as a strategy to work towards cultural safety. For example, the researcher in the researcher-participant relationship must be acutely aware of asymmetrical research encounters and develop strategies to mitigate imbalances in power in the researcher-participant relationship. Researchers must also aim to engage in a research process that fosters negotiation of identity and meaning within the researcher-participant relationship (Kirkham et al., 2002). Finally, researchers must recognize the link of essentialism to racism and discrimination; that is, the risk of ongoing constructions of "othering" the "other" (Kirkham et al., 2002).

Being aware of and practicing cultural safety was relevant to this study. First, I co-composed narratives with newcomers in Alberta who were living with HIV. It was critical for me to acknowledge, understand, respect and nurture the unique cultural identities of each participant I worked with. Each participant was unique in composing narratives of who they were in their home countries, and who they were as immigrants in Canada. It was important for me to anticipate the uniqueness of each participant and to safely respond to their needs, expectations and rights (Wood & Schwass, 1993). Second, the awareness of cultural safety facilitated 'bicultural' interactions with participants. Bicultural interactions acknowledge that the researcher too brings personal cultural realities, attitudes, and behaviors to the researcher-participant relationship, and suggests that these will have impact on the other person (Kearns & Dyck, 1996; Kirkham et al., 2002; Ramsden & Spoonley, 1994). Finally, the researcher requires reflexivity in relation to their own personal and cultural experiences, history, values and beliefs in order to experience a culturally safe relationship with others (Anderson et al., 2003).

# Chapter 3: Methodology – Narrative Inquiry

## Introduction

Narrative inquiry offers a way to inquire into people's experiences, to gain an understanding of how such experiences come to be, and how these may influence future experiences. It also allows researchers to understand experiences through a collaborative relationship with the participant. This relationship develops over time, in a place or series of places, where social interaction between researcher and participant facilitates the co-creation of narratives for inquiry (Clandinin & Connelly, 2000). The researcher and participant work together to discover, tell and reflect on experiences, within a shared inquiry space. Clandinin and Connelly (2000) further described the importance of experience in research:

> The social sciences are concerned with humans and their relations with themselves and their environment. As such, the social sciences are founded on the study of experience. Experience is therefore the starting point and the key term for all inquiry. (p. xxiii)

The turn to narrative is a turn from numbers to narratives in understanding phenomena. Further, it is a turn towards an engaging and deepened relationship between the researcher and the researched; a turn to the particular about a phenomenon, rather than the general; and a turn to blurred knowing and knowing in multiple ways, rather than singular way of seeking truth (Pinnegar & Daynes, 2007). The relational ways of being with participants and developing relationships embedded in time, place, and social and personal contexts are also central to narrative inquiry (Pinnegar & Daynes, 2007). Narrative inquiry acknowledges the multidimensional, dynamic, temporal and relational aspects of experience:

> It is a way of understanding experience. It is collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in this same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people's lives, both individual and social. Simply stated, narrative inquiry is stories lived and told. (Clandinin & Connelly, 2000, p. 20)

## Stories: A way of Knowing

Qualitative methodologies, like quantitative methodologies are used to answer research questions, and knowledge is generated through inductive processes and interpretations (Creswell, 1998). In qualitative methodologies, the researcher and participant are placed relationally to one another (Benner, 1985). This relationship situates both the researcher and participant in an engaging and meaningful liaison where stories of experience are co-composed and understood. Narrative inquiry, one of the interpretative paradigms, is a relational methodology that focuses on the study of human experience (Clandinin & Caine, 2013; Clandinin, Murphy, Huber, & Orr, 2010) and is embedded in time, place and a social and personal context (Pinnegar & Daynes, 2007). The assumptions, values and philosophy of narrative inquiry assume that knowledge is developed and generated for the purpose of discovering and understanding lived realities and experiences. Further, the researcher and participant work alongside each other in narrative inquiry and the inquiry often begins with experience as expressed in lived and told stories (Pinnegar & Daynes, 2007).

Carper (1978) described multiple ways of knowing in the discipline and science of nursing: the empirics or science of nursing; the esthetics or the art of nursing; the personal knowledge in nursing; and the ethics or moral knowledge in nursing. Just as Carper (1978) described multiple ways of knowing in the discipline of nursing, narrative inquirers also turn from singular ways of knowing towards multiple ways of knowing and understanding human experience (Pinnegar & Daynes, 2007). Historically, narrative inquiry as method focusses on “narrative knowing as a valid and important tool for knowing in the human sciences” (Pinnegar & Daynes, 2007, p. 25). Human experience and the memory of human experience lie mainly in the form of narratives, whether in the form of myth, oral stories, written stories and so forth (Bruner, 1991). Narratives are a version of people’s reality, not based on any form of empirical testing and verification, but rather on how people choose to construct narratives of experience (Bruner, 1991). The use of narratives is a way of knowing the world, of one’s reality (Bhatia, 2011). The telling and retelling of stories related to human experience occurs within a multidimensional, dynamic, and temporal space.

## The Three-Dimensional Inquiry Space

Clandinin and Connelly (2000) described the framework for narrative inquiry as a “three-dimensional narrative inquiry space, where inquirers travel – inward, outward, backward, forward, and within place” (p. 49). In narrative inquiry, the research problem or the phenomenon to be studied is articulated as a research puzzle (Clandinin & Connelly, 2000; Clandinin & Huber, in press). The researcher engages in the research process to search for meaning and to understand a particular phenomenon with the research participant. The research puzzle is placed within a metaphorical three-dimensional inquiry space: personal and social; past, present and future; and place (Clandinin & Connelly, 2000). Situating the phenomenon in this fluid, dynamic, ever-evolving space is unique to narrative inquiry as a methodology. It challenges the formalistic notion that a phenomenon under study is fixed and one-dimensional, happening at a moment in time. It supports the idea that a phenomenon under study has a history and a future.

In the spaces of *personal and social* (interaction), *past, present and future* (continuity), and *place* (situation), narratives are co-created by the researcher and participant. Inquiry is based on the inward, outward, forward, and backward movement along the dimensions of the inquiry space (Clandinin & Connelly, 1994; 2000). Moving inward refers to movement into the internal conditions such as feelings, hopes, reactions, and moral dispositions. Moving outward refers to the movement towards existential conditions, or the environment. Clandinin and

Connelly (2000) described the backward and forward directions of inquiry as the temporal aspects of experience – the past, present and future. Narrative inquiry is a recursive process for both the researcher and participant, moving between phases of inquiry, negotiating and working together in each phase. Further, Clandinin and Connelly (2000) stated that “to experience an experience, that is, to do research into an experience – is to experience it simultaneously . . . [in these directions]” (p. 50).

#### Ongoing negotiation: Relationships and dialogue.

When narrative inquirers enter the field with the participant, both the researcher and participant will experience shifts and changes, negotiating, evaluating, and maintaining flexibility and openness to a constantly changing landscape (Clandinin & Connelly, 2000). Negotiating relationships with participants means being aware of and able to respond to what is happening in the relationship. Clandinin and Connelly (2000) emphasized that the research landscape is always changing and that the relationships developed with participants will also change and evolve over time.

Negotiating transitions during the study is also part of the narrative inquiry landscape. For example, the purpose of the research could shift and be negotiated with the participant. While the focus of the current study was developed months before data collection began, there was a possibility that the purpose of the study would evolve. Also, while the research puzzle focused on the experience of living with HIV, a participant might consciously or subconsciously focus on their experience of living as an immigrant in Canada, with narratives of HIV intertwined in the predominant story of immigration and settlement. Interestingly, this occurred in the current study with participants' narratives of living with HIV becoming intertwined with other experiences that could not easily be separated. Other transitions include the beginnings and endings of narrative inquiries (Clandinin & Connelly, 2000). The narrative inquirer negotiates the final transition (i.e., formal ending of the relationship) with the participant. "It is critical to the trust and integrity of the work that narrative inquirers do not simply walk away when 'their time has come' [or when the study has ended]" (Clandinin & Connelly, 2000, p. 74). Narrative inquirers may continue to work with participants to transition the relationship, whether it results in the ending of the relationship or continuation of the relationship after the formal activities of the research are completed. Regardless of how the relationship transitions or evolves towards the end of the formal research project, it is important to not abruptly end the relationship, but to negotiate the relationship that will continue past the research project.

#### Walking into the midst of stories.

At the beginning of the relationship, both the researcher and participant bring into the field experiences that are embedded in a greater context of time, place, personality and sociality. Even at the first meeting, walking into the midst of stories, each person's stories of past, present and future influence each other's storytelling, and the inquiry process that occurs in the researcher-participant relationship. Therefore the relationship becomes a reflexive one, where both researcher and participant are engaged in the living, telling, re-telling and re-living of narratives.

#### Context of site and participants.

As part of the current study I worked intensely with three participants. It was critical to select participants who had experienced the phenomenon and who were willing and able to share their experiences (Creswell, 1998). Eligibility criteria for participants included: male or female; 18 years or older; an HIV positive diagnosis; migrated to Canada from a sub-Saharan African country where HIV is endemic; living in Alberta; able to speak English; willing to share their experiences and stories of living with HIV; and able and willing to provide informed consent to participate in the study. During the study, each participant chose a place to spend time together; participants chose places that were emotionally safe, convenient, and comfortable. It was important that I ensured a safe environment for the participant. Stigma and fear associated with HIV in this population could potentially affect participation (Donnelly et al., 2009; Tharao et al., 2006).

#### The people of this study.

Earlier, I described my narrative beginnings; the different stories and experiences that brought me to my doctoral program and eventually, this study. I now write briefly about the people who participated and contributed so much of their time to share their experiences. Their narrative accounts follow in the next three chapters, which are central to understanding and discovering more about the experience of living with HIV as an African immigrant in Alberta.

***Lesedi.***

Lesedi is a young man who was born in Ghana. He is 28 years old and he fled his last country of residence, Uganda, fearing his safety as a gay man. He arrived in Canada in 2010 and currently resides in Alberta with protected person status[5]. At the time of the study, he had very little or no contact with his parents and his siblings. He came from a wealthy family, by African standards. In recent years, he has become estranged from his family. Lesedi described stories of being turned away by his family, initially because of his sexual orientation and more recently, because of his HIV illness. Lesedi has struggled with depression for many years, which has influenced how he has coped with his HIV illness in Canada. He was diagnosed with HIV in Canada about two months after his arrival from Uganda. At the time of our conversations, Lesedi had been living with HIV for about eighteen months and was experiencing challenges related to settlement in Alberta. During the time that I spent with Lesedi, he shared many of his memories of childhood, his happy times with some of his family members, the sad times in his life, the fears he had towards his father and male family members, his determination to finish university and graduate education, his will to work and make his own life, and his struggles with his sexual identity and his HIV illness. Lesedi and I met in the summer of 2012 and after our formal research meetings

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[5] Ibid.

were completed in early 2013, we continued to keep in touch into the summer of 2013. I was always drawn into the stories that Lesedi shared with me. During the time I spent with him, I learned about his complex life and how his stories of experience seemed to intertwine with each other over time. For example, stories of experiences in childhood intertwined with his experiences as a young adult and as an adult. Spending time with Lesedi opened up many wonders for me. Even after our research relationship, I continued to wonder about the power of family relationships and how they shape one's life from childhood to adulthood. I also continued to wonder how the role of community, and the notion of found community (Lindemann Nelson, 1995) shapes one's experience of belonging and sense of identity.

#### ***Rita.***

Rita is a woman in her late thirties who migrated to Canada from Ethiopia in 1995, joining her father who was already living in Canada. She provided consent for me to contact her in August 2012. Rita has lived with HIV since 2003 and is a peer support worker in the community. She volunteers with people living with HIV, supporting them in their journey of living with HIV. Over the last few years, she has decided to take a break from volunteering in the community. I got to know Rita over a period of about ten months and remained in contact after our formal interviews were completed. Over time, I got to know a remarkable woman. I learned that Rita is very open about her HIV illness in the community, both in her local Ethiopian community, and in the general community. She has made the choice to be a voice for people living with HIV, talking about it in her community, promoting awareness and education, while trying to live well with her own HIV illness.  In the early part of our relationship, I often wondered about how Rita chose to be such a visible and open voice in her own community despite the powerful stigma and discrimination she faced.  The stigma and discrimination she experienced was not limited to her community, but was also something she experienced in her own family.  And yet, Rita continued to be a voice in her efforts to raise awareness about HIV in her community.  Over time, I learned about Rita's voice and resilience in the context of these challenges.  Even after our research relationship ended, I continued to wonder and think about Rita's complex life experiences and how these stories of experiences shaped her.

#### ***Sifa.***

When I first received permission to contact Sifa as a potential participant in my study, I was filled with anticipation: what would Sifa be like?  By the time I got connected to Sifa, I had met two people who shared their stories of growing up in Africa, living in Africa, making the journey to Canada and living with HIV in Alberta.  Each person I've spoken to has been remarkable; their life experiences and stories, unique and incredible.  So when I received permission to contact Sifa, I thought, what would her experiences be like?

When I called Sifa over the phone to arrange our first meeting, we spoke for a few minutes about the study.  I remember, her voice was soft, her English, though broken, was easy for me to understand.  Then I asked her a few questions like: where were you born? Where did you live before coming to Canada? When were you diagnosed with HIV? Sifa told me she was born in Rwanda. I remember thinking, Rwanda? And my heart sank. Immediately, I remembered the 1994 genocide that took place in Rwanda. I remembered reading about it years before and seeing images of the atrocities related to that time in history. Sifa mentioned that she fled Rwanda because of the fighting that took place in 1994. This meant that she lived through this time and experienced the violence that took place during this time, in some way or form. My heart sank because I felt that Sifa would likely have terrifying stories that she may (or may not) share with me. But I was even more distressed because I was about to meet a woman who had experienced a piece of history when humanity was at one of its worst times ever.

I got to know Sifa in the early part of 2013 and we continued to keep in touch over the summer of 2013. Sifa always chose to meet at her home. We always sat together at her dining table and I always felt a sense of calmness and peacefulness in her home. Many times, I found myself sitting quietly, and intently listening to Sifa as she spoke about her life. Sifa’s stories always took me to a place she once called home near Butare, Rwanda, then to the refugee camps where she lived, and back to Canada where she currently resides with her children. Though Sifa was quiet spoken and spoke with such simple words, her stories were very intriguing and powerful.

## Methods

### Recruitment.

I worked with several AIDS Service Organizations (ASOs) and the two Alberta HIV clinics to recruit participants. Earlier discussions with these agencies determined the extent of involvement of each agency in recruitment. Agency involvement in recruitment varied and ranged from displaying study information in patient waiting areas to actively providing study information to people living with HIV. Agencies provided general study information and the researcher's contact information to people who met the sample criteria. Between June and October 2012, three participants were recruited to participate and contribute to the study.

### Data Collection.

Conversations with each participant and field notes were the main methods used to collect field texts (also referred to as data in other methodologies). Relationships with each participant were developed over a period of ten to twelve months. A few open questions were developed for each participant to initiate conversation and eventually created a long-term, ongoing dialogue. During each conversation with participants, several opening questions were asked to open the inquiry space as a place to tell and re-tell life stories. These questions were not meant to structure conversations with participants, but rather to provide some stimulation for conversation. These topic areas served mainly as a tool for a "guided conversation" with each participant (DiCicco-

Bloom & Crabtree, 2006, p. 315). Sometimes in an unstructured interview the interviewer starts with a question like “Tell me about” and does not have to ask another question because of the richness of the participant’s response (Morse & Field, 1995). I met with each participant five to six times for one to two hours each time, over a period of ten to twelve months. Each meeting took place when participants were available and feeling well enough to meet.

## From Field Texts to Research Texts

### Creating field texts.

Being in the field and creating field texts is a complex process involving participation by both researcher and participant. In this study, field texts were developed from conversations with participants, field journal entries, and in some cases, telephone conversations, written communications, and photographs from participants. Conversations with each participant allowed for meaningful participation in telling and re-telling stories. The inquiry space allowed for in-depth conversations with each participant to share their life stories: childhood memories, life in their home country, migrating to Canada, living in Canada, and the experience of living with HIV.

During the research study, I kept a field journal. In this journal I reflected and wrote about the times I spent with each participant. It not only provided me a space to write about my interactions and experiences with each participant, but it was also a space for me to reflect and write about my wonders of each participant including untold stories and stories told. It was a place where I found myself writing a silent dialogue between myself and each participant, and as I progressed through the study with Lesedi, Rita and Sifa the field journal allowed me to further explore the narrative accounts co-composed with each participant.

Written communication, telephone conversations, and photographs were also used as field texts. I connected with participants over a period of about twelve months, even after the research relationship ended. Sometimes these informal connections were made to share good news about health or family relationships. One participant shared photographs from his life in Africa. It was a compelling experience for me; the photographs added a certain dimension to the stories told by this participant. They added visual images to the stories told, but also unfolded more meaning to these stories. It was important for me to attend to the relational aspect of co-creating field texts with the participant. The process of creating field texts was an interpretive and reflexive process. It involved the continuous reflection and challenge of asking critical questions about what was told, not told, and what this meant for the participant and their storied lives.

### Creating research texts – Data analysis and making meaning.

Field texts were eventually transitioned into research texts. This phase of narrative inquiry continued to evolve as a reflective process; thinking narratively, looking at field texts for meaning and social significance in relation to the research puzzle. Several tensions and challenges persisted in creating research texts (Clandinin & Connelly, 2000; Gergen, 2003 as cited in Clandinin & Huber, in press; Clandinin & Murphy, 2007). For example in the early phases of developing research texts, it felt intuitive to deconstruct field texts into themes and coded pieces of data. However, much thinking and reflection brought me back to the three-dimensional narrative inquiry space; working on the transition of field texts into interim research texts and narrative accounts that were situated in places and times of each participant's life. Further, coming to an understanding of the phenomena being studied was important, as opposed to finding a solution to a research problem. It was in this phase of narrative inquiry where I embraced a process in which I searched, re-searched, and searched again the meaning and understanding of a lived experience or phenomenon with the participant (Clandinin & Connelly, 2000).

## Ethical Considerations

There were several practical ethical considerations important to this study: issues of confidentiality; participant burden; and the need for immediate support for participants. These issues are part of the relational ethics that are central to narrative inquiry as a methodology.

Addressing confidentiality and issues of anonymity with participants at the beginning of the study was important for several reasons. First, there is much fear and stigma associated with HIV and AIDS in the African community (Donnelly et al., 2009; Este et al., 2009a, 2009b; Gray et al., 2008; Lawson et al., 2006; Tharao et al., 2006). Morse (1998) highlighted the importance of determining participants' views on anonymity as some participants may want to be recognized for their contribution to the research study. It was important, early in the research-participant relationship to discuss and negotiate the issue of confidentiality with each participant. At the end of the study, each participant confirmed and consented to the use or non-use of their real names. These issues were negotiated throughout the study.

Participant burden was another ethical concern in this study. As the researcher, I remained sensitive to each participant's physical and emotional health, and the level of their participation in the study. The intensity and frequency of meetings with each participant might have posed a burden on the participant. Again, negotiating meeting times, frequency and length of meetings with each participant was important to avoid participant burden. All meetings were conducted at the convenience of each participant as well as when the participant felt well enough to meet.

Finally, there were times during the study when I recognized the participant's need for additional support and services in the community. As a public health nurse and researcher, I was able to connect participants with services and programs in the community when needed. The data collection process was an intense experience for myself and each of the participants. There were emotional times during the relationships I had with each participant and it was important for me to attend to these emotional moments and be able to respond to these, in negotiation with the participant.

The ethical issues I present here are part of a greater relational ethics that are central to narrative inquiry. Relational ethics refers to how people attend to one another, as relational beings; it assumes the reciprocity of living with self, with others and with social, personal and physical environments (Bergum, 2003). In narrative inquiry, it is critical for the researcher to understand what it means to live in relationship with participants; that is “to live in collaborative ways in which we can co-compose and negotiate the living, reliving, telling and retelling of stories” (Clandinin & Caine, 2013, p. 169). Bergum (2003) described the importance of living reciprocally and recognizing our interdependence with others. This way of living is central to the researcher and participant relationship; living in relation to one another and paying attention to the stories of experience that are personal, cultural and historical (Bergum, 2003; Clandinin & Caine, 2013). Attending to the relational ethics of narrative inquiry also involves meaningful engagement in a relationship with the participant. This relationship is not limited to how the researcher communicates or what the researcher communicates to the participant (Hess, 2003). Rather, the relationship focuses on a way of being with each other within a moral space of attending to one another (Hess, 2003).

## Summary of Methods

After review and approval from the Health Research Ethics Board (Panel B) at the University of Alberta, Lesedi, Rita, and Sifa joined this study. All participants are living with HIV and migrated to Alberta from sub-Saharan African countries. I met with each participant five to six times for audio-taped in-depth conversations about their experiences. I met with each participant for about one to two hours each time, over a period of ten to twelve months. Data analysis occurred through an inquiry process of moving back and forth, inward and outward between field texts, research texts, and field notes. Research texts were shaped by questions of significance, the *so what* and *who cares* questions that addressed the personal, practical and social significance. Each participant's narrative account was co-created by myself and each respective participant. The written accounts were written by myself and then negotiated with each participant. The process of collecting field texts, analyzing and writing narrative accounts for each participant was an intensive process; it required much time for reflection, dialogue with each participant, negotiation, revision and continuous writing. As Clandinin and Connelly (2000) described:

> [Writing involves] a kind of 'back and forthing' . . . We write, we share, we receive responses, undertake revisions, and work through this process until we feel we have moved the text along as far as we can. (p. 167)

What follows in Chapters 4, 5 and 6 are the narrative accounts co-composed by each participant, Lesedi, Rita, and Sifa and myself, within the participant-researcher relationship and within the narrative inquiry space.

# Chapter 4: Lesedi's Narratives

## Walking Into the Midst of Stories with Lesedi

It's early July 2012, and Lesedi calls to let me know he finally moved into the city. We talk for more than a few minutes over the telephone. He mentions that he received some information already about my study and would like to meet in person. I can't make out his accent - British maybe? I'm not sure but his accent sounds very unique to me. He says he got some of the study information already from the nurse at the HIV clinic and would be interested in participating. He mentions very openly that he was diagnosed not in his home country but after he moved to Canada. He arrived in Canada less than two years ago. His spoken English is excellent and he is very articulate. He sounds like a well-educated person when he speaks. I ask him if he would like to meet to talk more about the study and what his participation would involve. Lesedi catches me by surprise when he asks if we can meet at a café for our first meeting. I offer a private meeting space near his current location, but he insists on meeting at a café near the place he is staying at. He gives me the address of where he is staying. I know that place. He doesn't name it, but I know it is a homeless shelter for people. So we agree to meet at the café tomorrow to talk more. A *meet and greet*, I explain to him and he agrees.

We meet the next day at a quiet café, walking distance from where he is staying. It's a beautiful summer evening and I walk to the café where Lesedi asked to meet. The sun is still shining bright; not a breeze in the air. There are many people walking the streets in their cowboy hats and cowboy clothing. It's the first night of the Calgary Stampede. I wonder what Lesedi must think when he sees all these people dressed like this. He's only been in the country for less than two years and in Calgary for a week! What does he think when he sees these people? I walk into the café and glance around. I'm a little early for our meeting and I find a quiet place to sit. There's no one inside the café. Looking around, I think that this might be a good thing. I don't know how this meeting will go. I didn't expect Lesedi to ask to meet in such an open space to talk. Will Lesedi be comfortable meeting me in this setting? I decide to move from the table I am sitting at to another table - a little further from the front where the baristas are chatting and working. This way, there's a little more privacy for Lesedi and me. I sit and wait. Suddenly the theme song from the 1993 film *Philadelphia* (Demme & Saxon, 1993*)* plays in the background and I am struck by the significance of this song and the memory of this film. I must have seen this film nearly twenty years ago as a young adult. It was about a man living with HIV and his experience of stigma and discrimination in his life and workplace. It's one of a few films that I could never forget – one that's always in my memory. And here I am nearly twenty years later as a researcher in the field of HIV and human experience. What a coincidence. I snap out of my private moment and look at my watch. It's about a minute before 6 o'clock. The anticipation is building up inside and I start thinking – what will he look like? What will he be like? Will he want to participate in this study talking about his life stories and experiences?

Will this meeting go well? I look out the window. I don't see anyone yet that could look like Lesedi. But then again, *what would* Lesedi look like - black, white, tall, short? I look out the window again, this time up the street and I notice a petite framed young man wearing a bright red baseball cap. Is that him? He's well dressed, but casual, wearing a pair of blue jeans, a shirt and a jacket blazer. He looks like he just came from work at one of the offices around here. Is that him? Then he walks into the café. I look up at him. By now, there are a few people having coffee inside the café. Maybe this young man is meeting his friends for coffee. But he enters and he looks around and I think, he is looking for someone – maybe this is Lesedi. I did give him a description of myself yesterday.

The young man walks over and says, "Añiela?"

I reach out my hand to shake his and say, "Hi Lesedi, nice to meet you."

Our meeting starts out a little quiet and we sit down and talk over coffee. After all the formalities of talking about the study and filling out forms, it takes only a few minutes for Lesedi to open up about himself and his life. I feel a little unprepared to hear Lesedi's stories of himself in the sense that this is only our first meeting. I wasn't expecting Lesedi to open up at this time about himself. At the same time, I feel comfortable and happy to sit with Lesedi and learn more about him. I sit with Lesedi a while longer and I give him the space to speak. I sense that he would like to talk more and tell me more about himself and I open myself to learning more about Lesedi. I hardly speak during our meeting – not because I don't want to or because I don't know what to say. Lesedi has much to share and I sit quietly and listen to his stories. As I sit and listen carefully, I try to piece all the stories and bits of stories in my mind that Lesedi is sharing with me. As Lesedi speaks, I process the information he shares with me:

*Lesedi suddenly left Uganda to flee the authorities who learned that he is a gay man. Originally born and raised in Ghana, he left his home country to study and then eventually to work in Uganda. However, Ugandan laws around homosexuality have made him flee this country, for fear of his safety. Upon arrival in Canada, he claimed refugee status. Presently, he is waiting for a work permit and residency status in Canada. He comes from a large family: seven brothers, two sisters and two living parents. One of his sisters passed away recently. His father is a wealthy business man in Africa. He is currently estranged from his family. His parents are from Christian and Muslim religious backgrounds. His mother is a devout Christian, while his father is a Muslim. When he came to Canada he decided to settle in Edmonton first, because he knew of an acquaintance there. Lesedi comes from a wealthy background, by African standards, he said. He has recently completed two graduate degrees in IT (information technology) sciences and in business administration and left a job working with a well-known global humanitarian organization. He learned of his HIV status as a result of his Immigration Medical Examination (IME) which was done in Edmonton. He received a phone call from the IME physician informing him of his positive HIV status. He remembers this conversation well and describes the shock he felt at that moment. Lesedi described how he still* *struggles with the reality of living with HIV, as well as his experiences and struggles of living as a gay man. Lesedi left Edmonton after about eighteen months hoping to start a new life in Calgary. In Edmonton he felt stigmatized by the only friends he had in that city. Lesedi came to Calgary for a job that was offered to him in his field of work. Lesedi arrived in Calgary a few days before our first meeting, homeless and was trying to find a place to live.*

After nearly three hours, we part ways from the café. As I walk away from the café, I think about my conversation with Lesedi. He shared so much that I feel a little overwhelmed with the stories he shared. I expected a brief meeting together to talk about my study and what participation would mean for Lesedi. *Missed opportunity*, I say to myself. I wish I brought my recorder, but I didn't expect to sit for a while to hear Lesedi's stories. I think about all the things we talked about while I drive home. When I reach home, I sit and reflect more about what Lesedi shared with me and I write in my field journal:

*I'm struck by how open he was with me during our first meeting. I didn't expect that at all. He is new to our country, he is newly diagnosed . . . but then again, what did I expect? I guess I was expecting someone to be very private about their life. But perhaps Lesedi needed someone to sit with and share a part of him. I imagine what it must be like to be in a new country, new culture, to not have a circle of family and friends nearby – and to be diagnosed with a serious illness. I feel a sense of humility to be a person whom Lesedi felt he could speak openly with. For me, it would not be easy to open up to a stranger about my* *personal life. For some reason, Lesedi felt he could share some of his life stories with me. Lesedi was a very articulate person; his English was very good and as I had wondered, he is university educated, recently finishing a graduate degree program in the United Kingdom. He told me that he comes from a wealthy family in Ghana. He told me pieces of his life story: how he came to Canada; why he came to Canada; his family; his diagnosis; his struggles with his own sexual identity; and why he moved from Edmonton to Calgary. I feel that there will be much to listen to when Lesedi and I meet again. When we parted ways earlier, Lesedi agreed to participate in my study and to share his life stories and experiences. Part of me feels a little surprised because he was diagnosed with HIV not even two years ago. From what I've experienced, and from what I know, many people are generally reserved and private about their life stories of living with HIV. I feel a modest sense of happiness to be a person that Lesedi feels he can trust to share his life stories with.*

I sit and continue to collect my thoughts about our first meeting. I try and piece his stories together so I can make sense of who Lesedi is on the surface. I know that we will have much time together in the future to explore his stories and life experiences further. I sit and reflect on our first meeting. What I heard tonight are only bits and pieces of Lesedi's life. There will be many more stories to hear and I feel that I will be entering a journey with Lesedi as he continues to share experiences of life and living with HIV illness. All that I heard today makes me wonder even more about who Lesedi is.

## Being in a Place of Stories with Lesedi

### Memories of childhood in Ghana: "When I was growing up I knew I was different."

Over time, Lesedi tells me different stories about his family: his mother, his father and nine siblings. He is the third youngest in the family. He is currently estranged from his family after they learned about his HIV diagnosis. As I listen to some of Lesedi's stories and memories of childhood, I imagine a happy, playful, innocent little boy growing up in Ghana who was extremely close with his mother until he finished university. His eyes light up when he speaks of his mother and their relationship when he was a very young boy. He smiles brightly when he tells me stories about his mother. As Lesedi shares his stories of childhood, I also imagine a young boy who became very sad and who felt extremely lonely and isolated when he recognized that he was different. Over the time that I knew Lesedi, he shares many stories of his childhood and family life.

Lesedi recalls memories from his childhood. He says, "When I was very small everyone used to say and tease 'Oh you, you are like a handbag for your mother!'. My mom and I, we had a very special bond that just developed. I always heard stories about when I was a baby, I just clenched on to my mother. We were so close. I would even push my little brother away if I saw him near my mother. Anywhere she went, I was always with her. When I was with my mother, I always felt I was with my friend. But not my father. I always felt insecure when I was with my dad – like I'm not at his level. But with my mom, I never felt insecure. I remember my mom's friends teasing when I was very little - that I was so attached to my mom like an accessory bag!" Lesedi laughs. But suddenly, his face changes, as if a painful memory suddenly enters his mind. His eyes look down and the joy in his face shifts to sadness.

Lesedi recalls, "Sometimes, my uncle would try to pull me away from my mom's side because he said it's not good. In our culture, they want the boys to bond with the uncles and the dad. But when I'd go with my dad and my uncle, I didn't feel comfortable. I would get so upset and I would cry. *I would cry, I would cry.* I always wanted to be with my mom - even with my mom's friends. I remember that I used to like dolls and other stuff, but I knew it was not accepted. When I got to age 5, I can sense it . . . that what I liked wasn't accepted in the culture. So even though I had that affection for those kinds of toys I was afraid to express it. I didn't like the things that boys did - sports, running around, gunplay, whatever. I just couldn't do it, so I never played that way. And the things I liked to do and wanted to do, what my heart liked and enjoyed . . . I didn't do it because my dad or uncles would beat me. So when I got older I found myself getting lonely . . . lonely as a boy."

Lesedi continues, "But when I was growing up, my mom was the only comfort I had! It was my mom. Even when I was in high school I was very close to my mom. And we stayed close until she really suspected I was gay. Then when she learned I was HIV positive, our relationship really got strained. That's when things changed and I never expected that to happen." Lesedi looks down again, places his hands on his head, and pulls the red baseball cap that he always wears downwards to hide his eyes, his sadness.  Lesedi's pain and anguish about his current relationship with his mom comes through in many of our conversations.  He continues, "When I was growing up, I knew I was different.  It was like I tried to be a boy or a man, but I couldn't do it.  I tried, hoping that I would become more like a boy or a man.  But I just couldn't feel that way.  My mom knew I was different, that I was gay from an early age."  Lesedi sits still for a moment and looks down at the table, recalling some experiences as a teen.  He continues, "Yeah, I tried acting like a boy . . . it was useless.  I tried so many times and I couldn't feel that way.  And I knew.  I knew my mom knew I was gay from an early age.  I can't tell you how she knew, but she knew.  What I do know is that she knew, but she did not accept who I was becoming."

Lesedi says, "I think she thought it was a phase for me.  I think she also thought that there was an evil spirit surrounding me and that she could help take that away.  My mom is a very Christian woman.  She's an evangelical Christian. When I was younger, I remember she believed so much in her faith; she was so active in her church.  I can remember several times when my mom took me to these rituals.  Even though I didn't know where she was taking me, I would go with my mom and I never asked her questions.  I remember when I was about sixteen," Lesedi recalls, "My mom took me to this place.  It wasn't something Christian though.  Even though my mom is Christian, she also believed in these other traditional spiritual practices.  So she took me to this place and we met this man. I think he was a traditional priest. He was not a Christian priest but like a traditional priest and I just remember one time . . . he bathed me in hot water. Then he took a chicken, put it in the water and sprinkled water all over me. I just didn't ask any questions. I knew they were trying to drown out the evil spirit from me. I remember seeing my mom giving that traditional priest a lot of money after that ritual. She really hoped that I would change and become more like a man. She took me twice to see a traditional priest . . . she really loved me though. I knew she really loved me. She really had a lot of dreams for me. I know that she wanted me to have a wife and children and I remember my mom tried different things to try and change me."

Lesedi continues, "When I was growing up, there were times that I felt like I disappointed my mom. And then there were times when I thought *'Okay, I have to live life for me, not for her'*. I've tried so many times to change my sexual orientation and to become more like a man. And now - I know it's something that I can't change. I've I accepted that now. But it was very difficult for me to accept. I had to struggle with it . . . *really struggle with it*. In my family and culture my mom never talked about me being different. It's like I was a taboo. I knew my mom didn't want our family and extended family to know that I was different. I think she felt like I had an evil spirit in me and so she kept me away from our family."

As I listen to Lesedi's stories over the time of his childhood, growing up and his struggles of understanding himself and his sexual identity, I begin to understand why he chose to leave Ghana and his family. The struggle of trying to live the expectations of his father and male relatives, of being a man, having a girlfriend, and having a family became a burden for Lesedi as he grew up. Yet, I still wonder how a young child makes sense of these struggles, of being openly teased, of feeling different. Each time I meet with Lesedi, his stories begin to build a picture of who this young man is. He is very intelligent and a quiet fighter inside. He constantly fought the battle of trying to become his own person: facing the expectations of his father and male family relatives; reconciling with who he thought he was and what he thought was just a phase in life. This young man worked hard in his studies, finished his university education, managed to complete graduate studies in his area of work, and eventually began to work for a well-known humanitarian global organization. I wonder if perhaps Lesedi's drive to work hard and become independent was a way for him to find himself and to discover that through his hard work and education, he would be able to put these battles aside and live his own life. It was when he moved away from his family in Ghana, that he began his life as Lesedi; not Lesedi, the different one in the family, not Lesedi, the one with the evil spirits inside him that made him different from his brothers; and not Lesedi, the one who was beaten by his father and uncles for not meeting expectations of being a man. Lesedi left home at the age of twenty two, as soon as he finished his undergraduate university education. As I think about Lesedi, I wonder what it means to always live counterstories, to be storied as different and otherwise. How do these experiences shape his identity over time and in diverse social contexts?

Lesedi says, “I wanted to get away from my family. I knew I was gay, but I couldn’t live as a gay man where my family was. I left my family early; I never felt like I was accepted or understood. Even though I had my relationship with my mom, I knew she still felt like I was going through a phase, like a certain period of development that would pass one day. But I left Ghana because I felt like I was not accepted as a person in my family.

“So when I moved first to the UAE [United Arab Emirates], I wanted to get away from my family. And I just felt like I had to do everything by myself and for myself. It’s so strange though . . . I knew I was gay, but I wasn’t living as a gay man yet at that time. I didn’t want to at that time. I hated myself so much and I didn’t even want to think about having any relationship with another person. But still, I felt like I had to try and live my own life; who I am. At that time, and even still today, I’m still trying to do that – be who I am. When I left home and began to work and work on my graduate studies, I still kept in touch with my mom and my siblings. I still did everything to keep my relationship with my mom. I sent her money all the time, even though she didn’t need it. I just wanted to do it to keep my relationship with her.”

Eventually, in the early years after leaving home, Lesedi relocated to Uganda from the UAE, where his work took him. It is here where he began to live his life more as his own, away from the social pressures of his family. It is here where he felt he was becoming more of who he really is.  Lesedi had his first relationship with another man in his new country.  It is here too, where he faced persecution for who he was finally becoming as a young gay man.  As Lesedi talks I realise that I have no sense of what it means to be persecuted and possibly killed for one's identity.

### Living life in Uganda: "People just hate gay people."

One day, I ask Lesedi about what life was like for him living in Uganda as a gay man.  As I sit and listen to Lesedi speak about Ugandan society and attitudes towards HIV and gay men, I couldn't help but feel some level of anger and injustice and I think - how *horrible*.  How horrible it must be to live in a society that marks you for being someone who is evil and immoral, when you're not.  How horrible it must feel to be sought after as a criminal for not even committing a crime.  I couldn't imagine living like a prisoner in my everyday life for no injustice done.

Lesedi says, "Being gay in Uganda was a crime on many levels.  The Ugandan government proposed legislation to criminalize homosexuality; society treated gay people differently than straight people."  Lesedi experienced harassment from men who belonged to some sort of a crooked citizen's police - finding, naming and outing gay men.  How can one possibly live in peace knowing that you were targeted as a criminal, even when no act of violence has been committed towards another living being?  It is difficult to imagine a life without the basic right to freedom to be who you are.  As I listen to Lesedi's experience of living in Uganda the sympathy I feel for him is overwhelming. I imagine life as Lesedi's in Uganda: living as a prisoner in his own body, living under the watchful eyes of people who deeply discriminate against and hate gay men. And as I imagine, I know that I am left with so many questions.

"I found myself in a society that was like Ghana," Lesedi continues, "I thought I was starting a new life but it's just the same. People there believe that being gay is wrong. People teach their children at a young age that this kind of behavior is wrong and people make children believe it. That is what happened to me. I knew I was different at a very young age. But I would never be able to identify this way because my family said things, did things to say 'that is wrong', that I'm not quite right. There's so much stigma about being gay and being a sexual minority. In my country or a country like Uganda, there is no help for people who struggle with their identity. There's no money in mental health, counselors, psychologists . . . there is no help for people like me who struggle with these things. I struggled with a lot of depression growing up and even to this day. In Uganda there are laws that criminalize homosexuality. It's one thing to have HIV, but it's another thing to be gay. If someone has HIV and is a heterosexual, there's still that stigma of having HIV. But if you have HIV and you are a homosexual that is more difficult because you not only have HIV, but you probably got it because you are *gay*." Hearing these words is a sad reminder to me that there are still people in this world who treat others with discrimination and injustice.

Lesedi continues to talk about life in Uganda and his experiences make me think about the experience of discrimination. What would life be like where people treat you differently because of your sexual orientation? It's difficult to imagine a life where there is no tolerance or acceptance of difference. I've experienced discrimination in my life as a child, living in a Calgary neighborhood where we were the only visible minority. My experiences mostly involved other children taunting me and my sisters for looking different than them. But Lesedi's experience seems extraordinarily harsh and complex. The discrimination and stigma he talks about seems so embedded in society that it would seem impossible to change the way society felt towards gay men living with HIV. Tolerance and acceptance of diversity has evolved in Canada, much of it supported through Canadian government policy. Government policies, such as those in Uganda, support society's discrimination towards gay men living with HIV. Reversing a society's attitudes towards gay men living with HIV would seem challenging, if not impossible.

Lesedi was faced with a multitude of factors that shaped his experience of being gay in his home country (Ghana) and Uganda, before coming to Canada. I can see that Lesedi experienced deep discrimination from many social sources: his family, his community and his society as a whole. One time, Lesedi tells me a story about his experiences of discrimination and harassment in Uganda. He says, "Even though police never came to my door directly, people have made me feel like a criminal for who I am or who they think I am. I've been in social settings where some men will say things like 'Are you a fag or what? Don't you have a girlfriend?' It's like they are attacking me. People just hate gay people. *That* is what I experienced.

"Sometimes, I've been forced to hire a girl to play the role of my girlfriend at some social settings. I do it to avoid the harassment. One time, a prostitute asked me for more money when she knew I was gay and that I was hiring her to pose only as my girlfriend at a social function!" It was as if *she too* belonged to the people who have harassed Lesedi in the past for being gay. Lesedi says, "Because I knew I was gay, I always felt afraid to get tested for HIV back home. Even though I learned about HIV and how to prevent HIV, I was still afraid to hear one day that I am HIV positive. I did my part to make sure that I wouldn't get HIV, but I still was afraid of hearing that one day I would have HIV. I just didn't want to be double stigmatized - gay *and HIV*. Those are two things nobody wants to have, at least in my country."

Over the course of one afternoon together, Lesedi tells me about the laws regarding homosexuality in Uganda. Later that afternoon, I go home and search the internet for more information about the proposed laws against homosexuality. I visit western media sites, human rights sites, and also sites that seem to support such laws. Something like this shouldn't even be debateable, I think to myself. It remains challenging to understand the political, social and cultural stories that shape Lesedi's life. I think back to Lesedi and his storied experiences of living within the very society proposing such laws. I continue to wonder about his decision to leave Uganda, to flee the country that sought him for being gay.

### Fleeing Uganda: "I feared that my life was in danger."

One afternoon, Lesedi shares his experience of fleeing Uganda. His story is striking, unimaginable and intense. I feel a mix of emotions as Lesedi talks about his experiences leading up to his sudden departure from Uganda. As I listen to Lesedi, I think - how could there be so much hatred from one human being to another? It's like a modern day witch hunt where people hunt down others and hurt them emotionally and physically, for committing things perceived as morally wrong.

Lesedi says, "In Uganda, I couldn't live my life safely as a gay man. I feared that my life was in danger and that's when I felt I had to flee." Lesedi continues, "I was coming out of a relationship when I started to go to some online sites to meet people. I met a man named Luke. When we met online, I learned we were kind of in the same situation. We were both gay, looking for a friend or relationship. So we became friends online and then we planned to meet in person. At the time, I couldn't tell that he wasn't gay; he told me he was gay and I believed him. We became really good friends; we got to know about each other and he learned much more about me – where I work, where I live, my phone number . . . we texted a lot with each other. I even felt like we were even very close to a relationship. We had sex together . . . Then one day he asked me for 2 million Ugandan shillings."

As soon as Lesedi tells me about Luke and his request for money, I think - 2 million Ugandan shillings? I don't know what the exchange rate is, but it sounds like a lot of money. I suddenly feel a small sinking feeling in my stomach and a feeling about how Lesedi's story would evolve.

Lesedi continues, "Luke knew I had a good job and that I was very stable financially. And I asked him 'Why do you need this much money?' Luke said he had some family problems. He said his mother was sick and so I agreed to give him one million shillings because I couldn't afford 2 million. One million shillings is about one thousand Canadian dollars. After I gave him this money, our relationship went on for a while. We weren't intimate anymore, but I still felt like we were able to still connect emotionally. After a few months, Luke asked me for more money and this time it was for 4 million shillings. When I told him I didn't have that kind of money, that's when I found out who he really was . . . Luke said, 'I work for the police department that seeks out homosexuals to report to the newspaper. I have your name, your phone number and I have proof that you are gay and you are promoting homosexuality in Uganda. So if you don't give me this money, I'm going to out you.' And *I knew* I was in trouble."

*What?* I think to myself. Is there such a thing where people can report people they think are gay to the authorities? How could this possibly be right or just?

Lesedi continues, "Then we met one day to have lunch together. Luke acted normal, as if nothing was happening. When I saw him that day, I still thought - *I couldn't tell that he was not gay* . . . but Luke, he targeted me . . . he is going to out me . . . the Rolling Stone Paper is going to release my name."

"What is the Rolling Stone Paper?" I ask Lesedi.

"It's a local newspaper that regularly publishes the names of homosexuals in Uganda." Lesedi says, "They list the names of gay people in the newspaper with their address, their work, and other personal information. Luke was working with the authorities to find men like me. He was going to have the authorities come for me. I knew he was blackmailing me. At first, I thought - *maybe he's just doing this to scare me to give him the money.* But then I learned that Luke was actually married with children. I knew right then that he wasn't gay and that he really was trying to out me. Luke said to me, 'If you cannot give me the money, I'm going to let the police know about you'. I knew I didn't want to leave Uganda. I pleaded with Luke and asked if we could somehow solve this situation. I offered him what I could give him in exchange for his promise to not report me to the authorities. We agreed on this arrangement. He left with my money promising me that he would not report me. But then – I learned from a mutual friend that Luke had given all my information to the police and that the police would be coming for me soon. This friend advised me to leave the country immediately if I didn't want to go to jail."

I see the fear in Lesedi's eyes as he shares his story. Lesedi's eyes widen and he continues, "Uganda is a poor country. The authorities will rush to come and get you - first to get money from you and then to throw you into a legal limbo

. . . there'd be no escape. Luke had all the proof: all our text and voice messages with each other, all the things that we did together, photos together . . . Luke had so much information to bring me into the legal system for being gay. It turned out that Luke provided all this information to the authorities before I had given him the money. I just kept thinking -

*I don't want to have a legal problem with the authorities.*

*I have invested here, I have a house here, I have everything.*

*I should just leave!*

*And then I can sell all these things that I have.*

*Luke had already given my information!*

*They had actually gone to my apartment, two times while I was away for work!*

*They were just waiting for me to be back.*

*My bank account was already frozen.*

*I am very afraid!*"

Lesedi shifts in his chair, sitting upright. He continues to share the whirl of emotions and thoughts when he fled Uganda. He says, "I remember it was about 4 o'clock in the afternoon. I called my boss to say that I had an emergency and that I would be out of country for a short period of time. Because of my work, I had an international visa so I could travel freely into the US [United States of America], Canada, Europe and Asia . . . anywhere. After I left a message for my boss, I tried to withdraw money from the bank, but my account was frozen.

And I don’t hesitate.  I went online with my credit card to find a plane ticket.  I thought *where will I go?*  I decided to buy a ticket to the US, since I have a visa for multiple entries there.  So I left the country that night.  I spoke to my housekeeper and asked her to keep the house in order until things are okay again and she agreed.  I landed in Philadelphia because I had a friend there.  I spent a few days in Philadelphia.  I knew I didn’t want to claim refugee status there because I knew that a claim would take a long time.  I didn’t like the feeling of not knowing my fate during a long process.”

Lesedi continues, “During the days I spent in the US, I tried to sort things out.  My bank in Uganda confirmed that they had a legal restraint on my account and assets.  Everything was frozen.  I could not access any of my money.  I phoned the Ugandan authorities.  And they said *‘You are wanted for crimes of homosexuality’* and that I must face the legal justice system in Uganda because the crime was committed in Uganda.”

I look at Lesedi, and find myself holding my breath for a moment as I listen to him.  I quietly release my breath and I feel a sense of disbelief – not because I don’t feel that this story is true but because I can’t imagine a society that would persecute its own people for reasons like this.

Lesedi ends his story quietly, “I knew I could not go back.  I would not be able to escape the justice system in Uganda.  And then I remembered that I have a friend in Canada and I got in touch with him.”

### Canada: "A place to start a new life."

While in the United States, Lesedi made the decision to go to Canada. Lesedi tells me that he had been to Canada three times before. He knew a few people in Ontario and in Alberta. After thinking his decision through, he decided to go to Alberta and managed to contact his friend. One afternoon together, Lesedi recounts his experience of coming to Canada.

Lesedi says, "I called my friend in Edmonton, Paul. Paul embraced me to come over. He told me he has a house, a wife and baby. I knew I didn't have anywhere else to stay because I no longer had any money. I wanted to come to Canada to try and resolve the issues that I had in Uganda. In my mind, my main purpose was to go to Canada and see how I can best resolve my issues, and then go back home to Africa. I arrived in Edmonton in late 2010. It was maybe December 2010. When I arrived, Paul and his wife welcomed me. They embraced me when I arrived in Canada. I stayed with them for maybe about four weeks. During my stay with Paul and his family, I was trying to sort out what I should do. I even talked to Paul about it, without mentioning my problem of being gay. I told him that I had some legal issues with the authorities in Uganda and that I could lose my house and assets back home. Paul seemed understanding and let me know that I could stay at their home for a while."

Lesedi continues, "Someone helped me find legal aid in Edmonton to help me with my situation. After talking to a lawyer, he suggested that I stay in Canada because of my situation with the authorities; that I was being sought after because I was gay. I considered filing a refugee claim here in Canada – I just felt like I couldn't go back to Uganda; and I knew that I didn't want to go back to Ghana. I don't have a good relationship with my own family. And my work – I knew that they would not discriminate me for my sexual orientation – but I was paranoid of them knowing that I am gay. With all of these things I had to think about, I decided that Canada could be a place to start a new life."

"After a few months of being in Canada, I accepted that I could never go back to Uganda. I had no other place to go. So that is when I started the process to immigrate to Canada as a refugee claimant. It was about a month after being in Canada that I decided to apply for refugee status in Canada. I had entered the country with a 3-year visa from my previous employer. When I applied as a refugee claimant, I was also given a temporary Canadian work permit. I looked for work and I ended up working as a temporary records clerk in early 2011. It was very difficult for me to get any kind of meaningful employment, but I found a job that paid about eleven dollars an hour. *Imagine!* It was so far from what I was earning in my previous work. As part of my refugee claimant process, I had to have an immigration medical exam completed. And that's when I was told that I was HIV positive."

### Receiving the HIV diagnosis: "I was shocked."

One late afternoon Lesedi tells me about his experience of receiving his HIV diagnosis. Hearing about his experience of diagnosis brings me to my own memories of the past: a place where I sat many times with people to discuss and debate ethical HIV testing in Alberta. These discussions were often attended by people living with HIV, people with family members or friends living with HIV, people from the federal and provincial governments, policy makers, decisions makers, people who worked in local AIDS Service Organizations (ASO), doctors, nurses, and other health professionals. Those conversations took place well over 10 years ago to develop just, ethical and comprehensive HIV testing procedures in our province. Listening to Lesedi's experience of HIV testing and diagnosis reminds me of these discussions I had with people many years ago. As I listen to Lesedi, I also wonder about the work I had done with others so many years ago and if it made a difference.

Lesedi says, "One day I received a message on Paul's home phone that I needed to call back the doctor who did my immigration medical exam. It was about a month since I went in for my medical exam when I got the message to call back. So I went to a pay phone and called the doctor back. And I'll never forget that moment:

> *'Well, it's sad news. You are positive,' the doctor said.*
>
> *'Positive? What do you mean?' I asked.*
>
> *'I mean you are HIV positive,' the doctor said again.*
>
> *'No! There must be a mistake, right?' I said.*

I felt that there was a mistake in what the doctor just told me on the phone and I just remember him mumbling over the phone about information on HIV and something about referring me to the U of A [University of Alberta] clinic. *I was devastated*."

At those words, I too feel devastated for Lesedi, for why was he given this news over the telephone? Why did the physician not interact with him in more meaningful ways? Lesedi continues his story about receiving his HIV diagnosis.

Lesedi says, "I wasn't even aware that I was tested for HIV for my medical exam. I knew I had a physical; that they took blood. I thought they were testing for something like malaria because I am from Africa. But I wasn't aware I was being tested for HIV. They never told me I was being tested for HIV. And so when I got the news over the telephone, *I was shocked*. I even disagreed with the doctor. I said *'No I'm not HIV positive! No! There must be a mistake, right?'* After a little while, I felt I needed someone to talk to. I felt that I could talk to my friend Paul. But when I told him my news . . . he gave me less than twenty four hours to leave his home. His wife was nervous about me being in their home - being with the baby. She did not want me to hold the baby anymore or be near their baby."

As I listen to Lesedi tell his story of finding out his HIV diagnosis and the events that followed after, I feel sadness. I am sad for Lesedi. I am sad that his friend asked him to leave his home. I am sad for the discrimination Lesedi experienced throughout his life. My mind is full of questions and thoughts. Later that evening, I reflect and write about Lesedi's experience of HIV diagnosis in my field journal:

*This was wrong. No one should be told news like this over the telephone. This is someone who came from a place where HIV was still perceived as a death sentence for many. How awful for Lesedi to be told over the phone that he tested positive for HIV! I think back to the many times I sat in a room with people living with HIV: The discussions and debates over what is ethical pre and post HIV testing counseling. The emotions and the arguments, from people living with HIV, people with family members and friends with HIV; the need to inform people that they were being tested for HIV; the need for people to prepare for a negative result or a positive result; the need to inform people of their HIV test result in person and the need to sit with people after learning about a positive HIV result to address concerns and worries. Somehow, this was not the experience for Lesedi. I don't believe he received ethical pre- and post- HIV testing and counselling...*

Each time I see Lesedi, I think about his experience of HIV testing and receiving his HIV diagnosis. I feel outraged about how Lesedi experienced his diagnosis. After a while, my private anger dissolves. Perhaps Lesedi's experience of HIV testing and diagnosis was an isolated event and not one that is typical in Alberta, but perhaps it was not. My regret for Lesedi and his experience of receiving his diagnosis remains and I wonder if Lesedi healed from this devastating moment in his life and how.

### Living with HIV: "If only HIV was a death sentence."

Lesedi's stories of living with HIV often intertwine with stories of other things he was experiencing in life: dealing with the physical side effects of his medications, his depression, lack of sleep, not being able to eat well, and his efforts to find stable housing and employment in Calgary. I learn over time that Lesedi lives with depression, something that he has lived with for many years. He describes his experience of depression when he was a child and young adult: a result of his childhood experiences of being punished for his sexual orientation. After his HIV diagnosis in Canada in 2011, his depression worsened.

Lesedi says, "Life after finding out I was positive for HIV was so overwhelming . . . it was difficult and dark. The fact that I was going to lose everything in Uganda and that I couldn't return home was difficult for me. It was depressing to be away from home in Uganda. I worked for so many years in Uganda and to know that I could lose it all, my life in Uganda, it was depressing. Then I was diagnosed with HIV, my depression got worse. Oh my God! I was mentally degraded. I felt like I couldn't appreciate a single day in my life. Every day that came to me was a struggle . . . It was a struggle to see the next day. I didn't want to see the next day. I actually cared less about the HIV and on some days I would think – *if only HIV was a death sentence*, I would have been glad to just die. My thoughts were really messed up after my diagnosis. It felt like it would have been okay if HIV could just end everything."

Lesedi continues, “I spent a very lonely life in Edmonton. I felt so lonely and just the memory of those days just makes me feel depressed. Sometimes, I would spend six, seven days in my room. I wouldn’t even want to look out the window. If I did look out the window, it would be blurred; foggy . . . there was no joy, no happiness, no peace for me. The social workers would tell me to go outside, go for walks. I tried to get out, but I couldn’t. I had no energy. I felt nothing. I felt hopeless. I wished so many times that I could just be somewhere else, alone, with no one else around. I had many days like that after I was diagnosed with HIV. My heart was so sad, lonely and I longed for something more.”

Lesedi tells me that he saw a psychologist in Edmonton who eventually helped him with his depression through cognitive behavior therapy [CBT]. He says, “Sometimes if I get really overwhelmed, I won’t allow myself to get to the point where I might go over the edge. If I see something now that is going to be stressful or depressing, I try to stop it. I try to not let these negative thoughts over power me. That is CBT – I do my best to think positive.”

Each time I meet with Lesedi, I worry for him, his physical and mental health and his safety. I ask him carefully each time how he is doing; how he is feeling and I make sure that he has the phone numbers to call if he is ever in a crisis situation. I consciously ask him carefully, so as to not make him feel inadequate or self-conscious about how he is feeling. I sense that Lesedi is a very intelligent and aware person, that he will be able to seek help when he needs it.

Lesedi’s experience of depression is intertwined with his experience of living with HIV and settling into a new country. He shares his experiences of discrimination, finding housing, employment, adjusting to his medications, and trying to settle in a new city. He often talks about these experiences as being stressful and affecting his mental and physical health.

### Being gay and HIV-positive: “I just don’t want to be double stigmatized, gay and HIV.”

One afternoon Lesedi and I meet again and as we catch up in conversation, Lesedi continues to experience difficulties in being gay and having HIV, even in Canadian society. Lesedi describes his experiences in his new rooming house; his housemates; and then some of the discrimination he has experienced in his life as a result of his sexual identity and HIV diagnosis.

Lesedi revisits a story he had told me before about how his family treated him for being different. He says, “This is why I am not involved here [in Canada] with the African community. I *know* that they won’t accept me if they know that I am gay.”

Lesedi continues, “Even though I am here in Canada, I do not feel comfortable in getting involved with the African community here. If they know that I am gay, they will see me differently . . . they will see me differently if they know I am HIV positive. In Edmonton, when I first arrived in Canada, I tried to get to know the local Ghanaian community. Eventually, I was getting asked things like ‘Oh where’s your girlfriend?’ or guys would say ‘Bring your girlfriend next time you come to our meeting'. Then I would say, 'I don't have a girlfriend.' And the men would say, 'I hope you're not doing that thing, right?' I just wanted to forget about them. I would just say, 'Come on man, just forget it, alright?'"

Lesedi continues his story, "This type of thing would start and I didn't like it. The men would ask me how old I am, why I don't have a girlfriend, why I don't have any kids yet . . . So that's why I just don't get involved in the African community here in Canada. There was another time when I started to go to an African church. So I would go to church and the first time I went, the pastor spoke to the congregation asking for volunteers to play the guitar and piano for their weekly services. Because I play both the guitar and piano, I offered to volunteer. But at one church service, there was a man who began to preach to the congregation, saying:

> *'Homosexuals are taking over the church!*
>
> *It's happening in Canada, it's happening in the U.S. [United States of America]. They want to take over the world!*
>
> *They are agents of the devil!'*

He was preaching on the immoralities of homosexuality and he began to quote verses from the bible, and condemning homosexuals. He asked the congregation to pray for homosexuals to change because homosexuality is a sin . . . At that moment I thought – how can I fit in with this community? I felt that I was driven away. After that service, I called the pastor and said, 'Thank you, but I cannot come to your church anymore.' And I just felt afraid."

Lesedi continues, "Even though I am in Canada, it still would not be easy to fit in with the local African community. When people encourage me to go out and meet people from the African community, I just say 'No'. It's not easy. If I see that people still carry that attitude and belief toward homosexuals here in Canada, it wouldn't be easy to be around that. And then they would suspect you of having HIV too. How could I fit into a community like this? It's hard! *It's really hard . . . It's really hard.* I know there could be people out there who would be accepting of gay men, but I just haven't found that yet. I like to think that not every person is bad or intolerant."

That evening, I reflect on my meeting with Lesedi and how difficult it must be to feel like you couldn't belong to a community or what it must feel like to not have the freedom to be who you are. My thoughts and reflections bring me back to my life when I was in my mid to late twenties, and I write in my field journal:

*I remember my life in my twenties – the same life period that Lesedi is in now. Life was very exciting and full of possibilities for me; his stories of working through graduate school and finding the most exciting type of work with a great organization resonates with me. In my mid-late twenties, I moved away from home, completed a graduate degree without any financial support from my family. I did it on my own and I felt great about this. When Lesedi described the feeling* *of 'doing it on my own' – I remember the feeling of when I did it on my own. I was on top of the world! It was scary, but it was exciting. I finished my graduate degree back then and found very exciting work with an organization that had many possibilities for me. I developed new friendships and I explored relationships with whom I wanted to get to know. I was never afraid of being judged or discriminated against. I was free to be myself, express myself, and to make my own choices in life. How difficult it must be to live like a prisoner in your own body - afraid of being who you really are with others. Feeling afraid to be judged and treated like an outcast for not living the expectations of others in your community and society. I think back to Lesedi's words – 'It's really hard . . . It's really hard' and I feel his pain and hurt as he described his experiences of stigma in his community...*

Lesedi was not free in many ways. His depression and struggles with his sexual identity were challenges that Lesedi experienced for much of his life. Before he came to Canada, Lesedi was not free in his society. His sexual orientation resulted in social isolation in Uganda. After arriving in Canada, he experienced similar social isolation. Lesedi had to cope with a tremendous number of stressful events in his life in a very short period of time: fleeing home; finding a new 'home' in a new country and culture; becoming estranged from his family; learning that he was living with HIV; coping with severe depression; coping with the physical changes in his body from the HIV illness and medications; finding work; becoming homeless; finding stable housing; and trying to stabilize physically, mentally and emotionally.

#### Family exclusion: “I didn’t choose to have HIV.”

One afternoon, Lesedi tells me a story that happened a few nights before our meeting. It was the night he learned that he would be moving out of the homeless shelter and into a boarding house with other young men. At that moment, Lesedi is completely happy to learn that a landlord accepted his application to rent a room in a house. His mood is happy; he looks alive and awake. He describes feeling overwhelmed with joy.

Lesedi says, “Last night I couldn’t sleep. I was so excited to finally have a room for myself and to know that I was going to be out of the shelter. I just couldn’t sleep. But I was so excited and happy that I thought, I have this calling card for 5 dollars- maybe I will try and call my mom and tell her how I’m doing and that I’m not homeless anymore. I really felt like it’s been a long time now, maybe she will want to talk to me again. I thought – maybe she has changed her feelings about me. So I said to myself – Okay, I will call my mom. So I went to the bathroom at the shelter, I got to the toilet, sat down and I closed the door. I sat for a moment and then I dialed my mom in Ghana. The phone rang and rang. I knew it was morning in Ghana. Finally, my mom picked up the phone and she said ‘Hello?’ I heard my mom’s voice and I felt so overwhelmed:

‘Yeah, hello mom?’ I said.

‘Who’s this, Lesedi?’ she said.

> ‘Yeah, mom. It’s me, Lesedi,’ I said.
>
> ‘I told you don’t call me! I told you I don’t want to have any demonic connection with you. I don’t want you to call me!! You are evil. Don’t call here!’
>
> ‘Mom, no, I just want to say hello. I miss you guys.’”

Lesedi bangs the table with his hands “BAM!” he tells me. “She just cut off my conversation and that was it.”

Lesedi’s face changes, his mood shifts to a deep sadness. His experience of reaching out to his mother was painful. After a moment, he continues, “I felt so happy to learn that I would have my own room and I felt some courage to call my mom . . . and she just cut off the conversation with me. After that, I felt like – I should better forget about them, right? I went back to bed and lay the whole night, thinking about everything . . . my future here . . . when I get a job, go to work and it’ll be my life. Mine.” I look at Lesedi as we pause for a second and his tears begin to fall. Lesedi sobs, “I’m lonely. I’m really lonely. There’s no friend, there’s no family, there’s no one, nobody. When I was growing up, I loved my mom so much. She was the only person that I wanted to make happy and because I knew my dad wouldn’t be there for me, it was my mom who was always there for me. But now, *my mom, my mom, my mom* doesn’t want to talk to me.”

Lesedi continues to sob as he describes his current relationship with his family, especially his mother. He hasn’t spoken to his mother for a long while since learning of his diagnosis about eighteen months ago. Lesedi becomes more emotional and I offer him the comfort of my hand on his shoulder. I too feel emotional, as a mother and as a daughter; I think about my children momentarily and my own mother. I think to myself how painful it must be for Lesedi to feel rejected by his own mother. The thought saddens me, but looking at Lesedi and his pain saddens me more. The mother-child relationship is supposed to be a special, unconditional bond between two people. In this moment my understanding of the bond between mother and child is challenged and perhaps forever shifted. How does Lesedi understand this bond? When Lesedi's tears stop, he tells me more about his mother.

Lesedi says, "It's been over a year since the last time that I talked to her. Her reaction the other night was the same reaction then. I thought maybe with time, she would try to change, try to understand. I want to tell her that I don't want to be gay, I didn't choose to be gay, I didn't choose to have HIV, I didn't choose any of this. If I had a choice, if I had the power - I would just erase everything. I love my mom. She's always had good intentions. She's not a harsh or mean mother. I love her." As I listen to Lesedi, I wonder what love means in this context.

### Intersections of experiences of settlement and living with HIV: "A rocky path."

When I met Lesedi, he had just relocated to Calgary, for a job that was offered to him, in his field of work. However, due to some delays with his work permit, he was not able to work immediately, which cascaded into a number of challenges for Lesedi. His unemployment meant he could not find stable housing. Not having stable housing made it difficult for Lesedi to cope with his HIV and mental illness – mainly the side effects of his medications. The less rest and sleep Lesedi had, the more difficult it was for him to manage his illnesses. I think back to his stories of his life in Uganda – his life of working hard as a young professional, owning his own home, having a housekeeper and now to his life in Canada. His life in Canada is a stark contrast to his life in Uganda. All of his belongings are kept carefully in a bag that he always had at our meetings. Some of his personal belongings sat in a pawn shop in Calgary. Lesedi was a homeless man for much of the time that I knew him, staying at a shelter. It was not an ideal place for a person to manage their HIV illness. He could not rest during the day, for people had to leave the shelter in the morning and were only allowed to return early evenings. He could not afford the quiet and stillness of a home because of his unemployment. It was a difficult time for Lesedi. And though he sought assistance from various programs and organizations, many supports in the community were at capacity and waitlists for services and support were sometimes three months to a year.

The following section highlights Lesedi's narratives of living with HIV and the intersections of his HIV illness with other areas of his current life that Lesedi felt were important to his HIV illness narrative, namely finding housing and employment.

#### ***Finding a place to call home.***

Each time we meet Lesedi shares his experiences of being homeless and the many challenges he faces as a homeless man, and the challenges of trying to find stable, affordable housing in Calgary. Though Lesedi's homelessness is a temporary and transitional period in his life, he shares that it is very difficult and challenging for him in many ways. "It's hard at the shelter – sleeping . . . everything. Some people are not treated nicely. It's like the workers stereotype people who stay at the shelter. For example, if you're in a shelter, you must be suffering from addiction or you are abusing drugs. Some people over at the shelter, they actually disregard the fact that people have to stay there because of poverty. It's like they treat everyone as if you are a drug addict. I had a hard time at the shelter because I felt like I was really downgraded. My self-esteem was affected because of the way I was treated. I was not happy and I felt like I couldn't do anything about it. I was humiliated one time by a worker because he thought I was on drugs, but I was just so tired and sleepy from not sleeping and from some of my medications. My biggest stressor since I arrived in Calgary has been my housing situation – being homeless. It is my biggest stressor."

Each time I hear Lesedi's stories of trying to find housing, I am reminded of the difficulties of finding affordable housing in Calgary. A delay in the processing of his work permit has resulted in him being unemployed. Lesedi feels this has been a critical factor in finding housing. Lesedi also feels that some people have even been judgemental towards him. One time, Lesedi tells me about one of his experiences with a landlord. Lesedi says, “One man was going to rent one of the rooms in his house to me. Then he suddenly changed his mind. I was very disappointed. I gave him a damage deposit and everything he needed. Then he asked me if I had health issues.”

“Health issues?” I say to Lesedi. I quietly think to myself that it is not a usual question to ask tenants.

“Yes,” Lesedi continues, “He asked me ‘Do you have any health issues?’ And I don’t want to lie to anyone about my condition – my HIV. I don’t want to be a liar to anyone. I’m very honest about who I am. So I said to the man ‘I don’t think I have any physical health issues, but I am HIV positive.’ And the man said ‘Okay, leave us your paper work and I’ll get back to you.’ And then later that day I got a message from the man and he said ‘Sorry, I can’t rent the room to you.’ I was so disappointed. But I just have to respect him and his decision. I have to be honest with people. If people don’t ask about my health, I won’t say anything. But if people ask me about my health, I feel like I have to be honest with people – especially if I have to live with other people in the same house . . . because some people might want to live differently with someone who has HIV, you know?”

At these words, I begin to understand a few things. I begin to understand that there is still discrimination in our society towards people who might not look physically well or may appear overly tired, or who are underemployed. But I also begin to understand that even from Lesedi’s perspective, he feels others would want to treat him differently or behave differently around him because of his HIV illness.

Over time, Lesedi manages to find housing in a boarding house in the city. There, he has his own private room and shared common areas like the kitchen and living room. When Lesedi finds this place, it makes a significant positive change in his life. He says, “It was stressful and frustrating trying to find a place and not being able to get the help sooner to find a place. Then, I had all these delays with my work permit . . . I felt so much regret coming here. But I have hope; that things will get better. I try now to look out for the good that lies ahead. On some days, it’s such a rocky path – some highs, some lows. I know I’m not completely okay in terms of my health - my physical and mental health. I hope that time will help. But now – my stress levels have been reduced a lot . . . now that I have a place to stay – a home. It’s not a place that I really like or cherish, but it’s something that will do for now. Being at this place has made me feel far better than I was a few weeks ago in terms of my physical and mental health. The stress was really making me feel unstable.”

### *Finding a job: “I’m not disabled! I want to work.”*

A few months pass and Lesedi and I meet again in February 2013. We meet to do a little paper work, to give him an update about the narratives I am writing about his life experiences, and to talk about how he is doing. Lesedi and I meet at a busy café over the lunch hour of a workday. As I wait for him, I wonder how Lesedi has been over the last few months. The last time we had contact was in December 2012, by email. In December, he told me he was still struggling with health issues: medication side effects, sleeplessness, weight loss, poor nutrition, and possible liver problems. He described how his doctor is still trying to adjust his medications to help him. I wonder - what does he look like? Does he still look frail and thin or has he been able to eat better and gain some weight? I find myself thinking about the first time we met – it was a hot summer day in 2012. The last time we met, it was a warm Fall day in 2012. And now I am meeting Lesedi on a cold winter day in 2013. I think about how much time has passed and wonder how Lesedi has managed over the last while. As I wait for Lesedi to arrive, I notice a young black man looking around. He is wearing casual clothing, slacks with a sweater, carrying a bag over his shoulder. His hair is light brown and combed into an afro. Is that him? I look closely at the young man and see that it's Lesedi. I can see his face, his eyes, his hair – he is not wearing the red baseball cap that I always saw him wear before. We greet each other and sit down over coffee.

I look at Lesedi and he looks much different from the last time we met. I've never seen him without his red baseball cap. As we talk, I clearly see his entire face and his dark brown eyes. Lesedi says, "I just came from job training. I found a job at a bank doing administrative type of work. The hours of the position are from 6 o'clock in the morning until 2 o'clock in the afternoon. It works for me. It will work out with my medical appointments." He continues, "If I were to work regular office hours, like nine in the morning until five in the afternoon, it would be hard to regularly ask for time off to attend my medical appointments. So this schedule will work for my medical appointments."

I ask how Lesedi has been feeling and I learn that he has experienced some difficult times at the boarding house where he lived. He describes how one of the roommates began to tease and taunt him for the way he looked, for looking tired all the time, and for his forgetfulness. And finally one day the roommate took the taunting so far that Lesedi reacted angrily towards the roommate. Lesedi says, "I had a fight with one of the roommates. He was not nice. He's always teasing me and then one day I just got so mad at him, we got into an argument." Lesedi continues, "I told my doctor and social worker about the incident at the boarding house and the social worker helped me to move out of the boarding house into transition housing in the community. I am now at a place that is safe and quiet. The doctor said it is a better environment for me." From what Lesedi describes, his new housing arrangement would give him the peace and stability of a home. Although it is temporary transitional housing, he will be able to stay there until he becomes settled and while he continues to explore his employment options.

Lesedi continues to tell me about his current employment situation. He says, "I just found this job. It pays ok, but I need to work. My health is good. My liver is fine after I had those tests. I'm eating a little better than before but I'm still learning to manage the timing of my medications. I have to time them with my food so I don't throw up." Lesedi continues, "Mentally, I feel better. They adjusted my meds so it's better now."

I quietly feel thankful that Lesedi has improved since the last time I saw him. We talk more about his new job and I say, "Does your social worker know you are working now?"

Lesedi says, "No. I know they will say I am not well enough to work. But I want to work. The social worker even completed an application for Alberta AISH [Assured Income for the Severely Handicapped] funding. I got approved for AISH from the provincial government. But I went to the internet to read more about what AISH is. I read that it is financial support for people with disabilities! I said to myself – I am not a disabled person! I do not need this money. I need money, yes. But I do not want it from this program. I can work and earn my income through work. I am *not* a disabled person – they should give this money to someone who really needs it."

We sit for nearly an hour, talking about how Lesedi has been doing. Partway through our conversation, Lesedi pulls out his medications and says, "It's time for me to take my medicine. I've learned to time my medications so that I don't get nauseated or sick from them. Sometimes if I don't time this out right, I get nauseated with the medications and I throw up." As we continue to talk, he carefully pulls out his medication bottle and takes out a tablet and takes it by mouth, followed by a sip of his coffee. Lesedi continues, "My health is good now. I have my medications; I take my medications. If I didn't have these medications, I wouldn’t be doing good. I think my new housing arrangement will help me get better too.” We continue to visit for a little while longer until we part ways again.

## Closing Reflections

As I write this narrative I think of Lesedi, whom I have recently been in touch with. As he continues to live his life, adjusting to a new housing environment, managing his HIV and mental health illness, and finding stable employment – I can only hope that he continues to respond well to his medications to get well enough to settle into the city. He tells me that he also doesn’t give up on reaching out to his mother, whom he loves very much. He tells me she is a wonderful mother and how much he loves her, so much so that he says he will continue to reach out to try and repair his relationship with her. Lesedi feels that his mother will always have good intentions for him. I hopefully wonder if it is only matter of time before she can accept Lesedi for who he is as a gay man.

I’ve seen this young man try very hard to get himself on his feet again in the time that I got to know him. I think about who he was just 3 years ago in Uganda. I think back to the time when Lesedi showed me a picture of himself taken just 3 years prior to us meeting. I remember my thoughts at that moment:

*I am astounded. Who is this young man I see in the photo? He is fuller, rounder, his eyes so bright and his smile so wide. His skin is a beautiful shade of brown and he looks so alive. I can hardly believe it is Lesedi in the photo. Is that* *really him? And when I look closer at the photo, I can see Lesedi - he is the young man in the photo. It's him! He looked happy and bright. As he holds the photo of himself, I look at Lesedi, sitting before me. His eyes stare down at his own photo; then he looks up at me with his dark, hollow eyes. The juxtaposition is stunning. In just 3 years, Lesedi has become a thin and fragile looking man. The clothes he wears hangs on his body, as if they are a few sizes too big. His posture and expression emits uncertainty and sadness; a stark contrast to the Lesedi I see in the photo. His eyes are dark, empty and tired. His face- hollow, full of sadness and loneliness. At this moment I feel immensely sad for Lesedi . . . I feel a sense of sadness in the room, between us as we sit quietly before this photo. Looking at Lesedi in front of me and his photo from 3 years ago speaks a thousand words of what Lesedi has experienced in such a short period of time.*

As a researcher, I can only offer him my moral support by being present and by encouraging him to see his physicians and other health professionals who are taking care of him and helping him manage his HIV illness and mental health. As a human being, I feel his suffering and pain and wish I could do much more to comfort him during this time. Lesedi has a long road ahead of him as he continues to cope with his HIV illness and his new life in Canada. He is coping with an overwhelming number of events in his life and I only hope that he will find himself one day - where he feels like he once did in the photo taken just 3 years ago.

# Chapter 5: Rita’s Narratives

## Walking Into the Midst of Stories with Rita

It’s a hot summer day in late July 2012 when Rita and I agree to meet for the first time. It’s going to be our first meeting together to talk about this study and to answer any questions that Rita might have about participating. I leave my office early to drive out to our meeting location in an ice cream shop. As I drive around the neighborhood to look for the ice cream shop, I see many people walking leisurely on the sidewalks in no particular hurry. It’s as if they were simply enjoying the hot summer day. I notice the diversity of the neighborhood: Vietnamese restaurants, an Ethiopian restaurant, car shops, hair salons, ethnic local grocers; and people from diverse cultural backgrounds. I know this neighborhood well. When I was a child, I remember that my family used to drive to this neighborhood to get our groceries. We used to get groceries from a small grocery store owned by a Korean family. I look for that grocery store and it’s no longer there. That was a long time ago, I think to myself. As a child, I never noticed how diverse this neighborhood was; but as I grew older and became more aware of my surroundings, I learned that this particular neighborhood is as diverse culturally as it is linguistically. It remains as diverse as it was more than 30 years ago, if not more. It’s no wonder that it is called “International Avenue.” They say you can see the world just by walking down the 35 blocks of International Avenue. As I leave my car and walk to the ice cream shop, I pass by a mother pushing her toddler in a stroller. I smile at the child and she returns my gesture with a great big smile as she waves her hand. For a moment, I feel thankful and lucky to live in a city where people from diverse religious and cultural backgrounds can live together peacefully; for a moment I too wonder about the tensions that are not always visible to the outside. As I approach the ice cream shop, I wonder what Rita looks like. We actually never described one another over the phone. I think that if we both look like we are looking for someone we should be able to find each other. As I approach the shop, I see a woman sitting at a table at the outdoor patio. I wonder, is that Rita? Then another woman comes out of the shop to greet her friend. That is not Rita. Then I notice a woman with beautiful dark curly hair sitting at the outdoor patio, on a bench, quietly enjoying her ice cream cone. Is that Rita? The woman looks like she is enjoying her quiet time and her cool ice cream on this hot sunny day.

“Rita?” I say to the woman as I approach her.

“Hi Aniela,” she says quietly as she invites me to sit beside her.

About an hour passes as we sit under the summer sun. We talk about the study, Rita’s willingness to participate, and fill out the paper work for participation. Then Rita begins to talk about her life. As she shares short stories about her life and her family, I think about how fortunate I am to have met another person who is willing to share their experiences. Rita catches me by surprise at our first meeting. She is very open with me, telling me about her journey to Canada, who her family is in Canada, her children, her partner, and when she was diagnosed with HIV and AIDS. By the end of our first meeting, Rita agrees to participate in my study. Before we part ways, we exchange our contact information and agree to keep in touch until our next meeting. We agree to meet more times over the next few months, as long as she is feeling well enough to meet. Later that evening, I write in my field journal:

*I tried not to set an agenda at our first meeting, other than to talk about the study and answer any questions. I just don't want to be unfair and expect anyone to open up with me at our first meeting. But I have been so surprised by Rita. She opened up so quickly and I welcomed her openness. I am amazed that I have been able to connect with Rita in this way. It's one of the things I have always enjoyed and nurtured over the years of being a nurse. I've always enjoyed the privilege of sitting with another person to hear their stories; just listening to what they have to say. Rita was very quiet spoken. After we talked about the study and her willingness to participate, she started to tell me about herself. Of course, I had no recorder with me. I tend to not take a recorder at these first informal meetings. I always think that that could be intimidating for both me and the participant. Today, when I was with Rita, it's like we were just two people sitting outside enjoying the summer sun, talking like friends.*

*Rita came to Canada about fifteen or so years ago in 1995. Well, I guess that would be 17 years . . . I hope that will be okay with my co-supervisors. I think we said participants should have immigrated to Canada within the last 10 years. I recall conversations about concerns of people not remembering their stories beyond 10 years. But at this point, I don't see any significant reason why I* *wouldn't be able to include Rita. I have no concerns about Rita not remembering her life when she came to Canada and when she was diagnosed. She had a stroke in 2003, which led to her HIV diagnosis that summer. Her dad sponsored her to Canada – he has been living in southern Alberta now for thirty or so years. Rita mentioned that her dad is well known in their local Ethiopian community. She has a partner. They live in a house they own together. She doesn't work at the moment; she used to work at a large hotel for many years before she became sick. She has two grown children and a grandson. Rita also volunteers in the community. She is a peer support worker for the local AIDS Service Organization (ASO). She works with other people living with HIV. Rita also mentioned that she is involved in her community to raise awareness about HIV. She does radio interviews and other interviews, talking about her illness and trying to raise awareness in her local community and in the community in general.*

*I couldn't help but think, "Wow" while I was listening to Rita. I was in complete awe as I listened to some of the stories she shared with me. She's now lived with HIV for a long time. What strikes me the most is her work in the community, being a voice in the community for HIV awareness and also being a support worker. I wonder how she got involved in the work she does in the community . . . Rita looks well. But then again – what does someone living with HIV look like? Rita mentioned that she has responded very well to her medications over the years, except for the neurological effects of her HIV. Rita told me that her father and two children live in the city. It made me wonder what* *her relationship is like with her father and children. Are they close? What do they think about Rita and her HIV illness and work in the community. How has Rita's HIV illness affected her relationship with her family? I've met people before, living with HIV where family relationships were broken or strengthened. I wonder for Rita, what her illness has meant for her and her family. . .*

## Being in a Place of Stories with Rita

### Rita's memories of childhood.

At our first conversation, Rita arrives early. We settle down at the table and talk about the study a little more. Rita tells me she is very open about her illness and her life. I wonder, what has made Rita feel so open to talk about her life with me and the people in her community? She is the first person I know from the African community who is open about her illness and who talks willingly about HIV. I wonder how Rita decided to be so open with others. We bring ourselves back to the conversation and Rita says, "What do you like to know about me? I can tell you about anything you'd like to know." There's so much I'd like to learn about Rita. I say, "Let's start from the beginning. Tell me about where you came from and when you came to Canada." I say this, hoping that it will give Rita a good starting point, with so much she says she can talk about.

Rita says, "I was born in Ethiopia. My father is the one who sponsored me to come to Canada in 1995. My mother, she died when I was 4 years old. I didn't know her. I don't even remember her at all. I grew up with my grandfather who raised me with his wife – my grandma. I have four siblings – two sisters and two brothers. There are five of us and I am the oldest. My two sisters live in eastern Canada now and my two brothers are in Europe. We have different mothers. And because I was raised by my mother's father, we did not grow up together."

Rita continues, "For some reason, when I was young, if someone said 'Don't do it', I will do it anyways. I still have that kind of a habit today. I remember when I was a little girl, my grandma said to me 'There is a fire, don't touch it', but I just touched it anyway to see what would happen. My grandparents never explained why I shouldn't do certain things. They would just say that I would go to hell if I didn't listen. I am a Catholic. I still believe in God. My grandparents, they tried their best. They would often say 'Don't do it or else you will go to hell' - that's the Catholic way. They don't teach you how to use protection or birth control. These are not allowed in the Catholic religion. So when my grandparents said 'Don't do it', I just did things I wasn't supposed to do anyway." I imagine Rita as a vibrant, curious little girl as she tells me about her childhood days in Ethiopia. She talks about many times when she wanted to test the rules of her strict grandparents. She tells me stories about her grandmother who raised her. As a Catholic, Rita's stories of being raised Catholic resonate with me. I remember how strict my parents were growing up and the whole message around *'If you sin you will go to hell'* or *'God will punish you if-'*. As Rita tells me about growing up Catholic, I understand what she means about these rules to follow in order to avoid going to hell. God was very present in my life when I was growing up. As a child, I always remembered the watchful eye of God as I too tested rules and boundaries - very much the same way Rita did. It’s an odd, yet comfortable feeling to sit with someone who I am just getting to know, who understands the watchful eye of God and strict Catholic parents. I wonder how the influences of Catholicism have shaped and continue to shape Rita’s life. Knowing already that Rita is living with HIV, I wonder about how she experiences the influences of Catholic practices; practices that can add to a sense of shame, exclusion, and also alienation. Then Rita tells me about her pregnancies.

Rita says, “My grandparents, because they are Catholic, they said things like ‘If you have sex before you get married you’ll go to hell’. When I was a teenager, it’s like I always tested my grandparents and what they said. I was 15 when I had my daughter and I was 16 when I had my son. I was too young to have them. But I know it is a sin to end the pregnancies so I had them. When I had my daughter, they took her. I never held her. I never breastfed her – *nothing*. My family, they said, ‘She’s not your baby. Don’t tell anyone’. It was such a stigma for me to have babies that young. If someone has a baby before getting married, people call those children bastards. You know, I brought shame for the family at that time. I brought two kids to this world. My grandma lied to everyone. They didn’t tell anyone they were my kids. I didn’t tell anyone about my kids. I listened to my grandparents. I had to - otherwise they would have kicked me out." As Rita tells me the story about having her children as a teenager and not being able to hold her babies, I see the sadness in her eyes and I feel an incredible amount of sorrow for her. When I was a teen, my responsibility was to go to school, study hard, listen to my parents and help with chores around the house. I couldn't imagine the responsibility of bringing two children into the world as a teenager. As a mother now, I can't imagine not being able to hold a child that you once carried for nine months to bring into the world. Rita tells me that her children were raised by other family members and eventually their biological father. They never knew Rita as their mother until they became teenagers.

### Coming to Canada - "It was my dream."

After Rita gave birth to her two children, she continued her schooling and finished her education. When Rita was a young adult, she learned about her biological father. Her grandmother was dying and three days before she died, she told Rita the truth about her parents. She learned that her grandparents were the ones who raised her as their own daughter. It was then that Rita learned that she had a biological father and that he was alive. Rita tells me that she looked for her father and after finding her father's family in Ethiopia she received a phone call from her father who was already living in Canada. Rita says, "I never knew who my dad was until my grandma died. That's when I found out about everything. I found out that my biological mother's parents took me and raised me after my mom died. My father never saw me after that and I never knew I had a biological father until my grandma died.  She told me everything 3 days before she died.  I started to look for my dad.  I found his family in Ethiopia; my father's parents. When I met them – they knew who I was!  All those years they knew about me. They told me my dad was already in Canada.  Then I got a phone call from my biological dad.  That's the first time we met, over the phone.  He was in Canada, I was still in Ethiopia.  We talked all the time on the phone.  He sent me money from Canada – I did more school.  Then he sponsored me to come to Canada and I came to Canada in 1995.  It was the first time I met my dad in person – in 1995.  I love my dad.  He is the one who brought me here."  Rita's eyes light up when she talks about her father.  I can only imagine the emotions that Rita felt at this time in her life; learning about her biological father and being able to reunite with him and develop a father-daughter relationship with him.  I wondered what it meant to develop this relationship as an adult: What happened for Rita and her dad without shared memories of growing up or watching your own daughter grow?  I wondered how their relationship would unfold over time, first in different geographical places, then in the same geographic place, and then with the impact of Rita's HIV illness.

Rita continues, "My father is the one who brought me to Canada.  He was already in Canada and he sponsored me.  I came to Canada in November 1995 . . . *November 4, 1995*.  That was the best day of my life!"  Rita's face lights up with a smile as she recalls the time she arrived in Canada, under her father's sponsorship.  Rita recalls with excitement, "I came to Canada and I felt alive!  It's like I arrived and I said, 'Look at me – I'm here! It's the best country ever!'" It was also the time that Rita told her own children that she was their biological mother. I can hardly imagine what it means to live a secret story of motherhood for so many years.

"When I left Ethiopia that was when I said to my kids: 'I am your mom. I will take you to Canada too. Just wait.' It was at the airport when I left Ethiopia. That was when I told my son and daughter that I am their mom. They didn't know I was their mom until that moment. At first, they didn't believe me. It wasn't until I started working in Canada and I started to send money to them and their father. We started to talk on the phone when I was in Canada . . . 'What do you need? I'm your mom' I would say to them. They always knew me as their sister, but now they know I am their mom. It was my dream to bring my kids to Canada. It was my dream for my daughter and son to go to school. My daughter went to high school here, but she didn't go all the way and that was my dream. But my son . . . no. He only finished Grade 7 in Canada. That's *it*. He went to school for 3 months and *that's it*. He dropped out." I can see the sadness and disappointment in Rita's eyes as she tells me about the dreams she had for her children. Rita continues, "Every time I see my friends and their kid's celebrations – like graduation – I don't go because I know I will cry. It's not that I am jealous. *No*. It's because I wish so much that my son . . . *I want to see my son graduate*."

Rita realized her dream of bringing her children to Canada. Between 1996 and 2003, Rita worked in the Alberta hotel and tourism industry. She tells me she worked very hard – it was all part of her dream - to come to Canada, find a job, work hard, buy a car, buy a house and to bring her children to Canada. Her son and daughter arrived in 2003, the same year that Rita was diagnosed with HIV. Not only was it the same year that her children arrived, but the very same week that she was diagnosed with HIV and AIDS[6].

“If I wasn’t sick . . . maybe I would have been able to guide them better. It was very hard for my kids – the culture shock. I wasn’t there to show them the way. I wasn’t there for them because I was in the hospital for 8 weeks after they arrived in Canada. And even after the hospital, I was not well. I was in bed recovering from the stroke. I couldn’t even shower or do anything. My right hand and leg were shaky and I thought I was losing my mind.”

Over time, Rita talks more about her life. I begin to understand the events of her life and how the HIV diagnosis – the diagnosis itself and the timing of her diagnosis affected her entire life and those around her: her children, her father, her partner and herself.

### Receiving the HIV diagnosis - “It wasn’t easy.”

The summer of 2003 was a life changing time for Rita and her family. Up to that point in time, Rita had never been sick; she had never even had a cold or flu. But it was the summer of 2003 when her body suddenly became sick for no apparent explanation or reason that Rita could think of, until physicians tested her for HIV. Rita recalls, “It was my day off from the hotel I was working at. I

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[6] When Rita was diagnosed with HIV in 2003, she was also clinically diagnosed with AIDS.

wasn't feeling well that day. But the months leading up to that day, I was losing weight, I couldn't eat, I had big headaches . . . and I just *didn't* want to talk to anyone. I went to see the doctor to ask what could be wrong with me. He told me I had depression and he gave me anti-depression pills. But still . . . even with these pills . . . something was wrong. I remember that I had a skin rash that summer – I didn't know what it was. It's like I had many mosquito bites on my legs. My skin was covered in a rash of different colors. Then I learned it was shingles. But still, I didn't know I had HIV . . . I didn't know what was going on. My partner kept saying 'Something is wrong. Let's go to the hospital' and I would say 'No'. You see, my children were on their way to Canada. I didn't want to go to the hospital unless my kids were there with me. So after a week that they arrived in Canada, like the exact same week that they arrived, I ended up in the hospital. It was my day off that day and I ended up in hospital. I just passed out – I fainted and my partner carried me into the hospital. I had a stroke."

I feel shocked by Rita's story of having a stroke; she is so young to have had a stroke, I think to myself. Rita tells me that much of her memory from this day has been affected because of the stroke. Much of her story about being diagnosed and the 2 months she spent in the hospital was pieced together from what she could recall and from what her family has told her. As Rita tells me her story of being ill, having her stroke and finally being diagnosed with HIV, I can only imagine the range of emotions that she experienced during that time: confusion, fear, sadness and hopelessness. For Rita, she never thought she would ever be exposed to HIV. As Rita talks about the time when she was finally diagnosed with HIV, she describes feeling shocked, and then scared. The fear of HIV and dying was strong for Rita because in Ethiopia, Rita always heard of people dying within years after being diagnosed with HIV. Rita also felt confusion, mostly because of the stroke she had. She shares stories of how her emotions played out during her experience of diagnosis. Rita continues, "I remember when the doctor told me that I had HIV . . . I thought I was going to die. I was tired and I was so tired to live. I was a mess at that time in the hospital. I peed on myself, I vomited, I couldn't eat. *I was a mess.* I couldn't walk - I was in a wheelchair or in the bed. For a while, they couldn't figure out what caused my stroke, but then they finally tested for HIV. I remember that moment."

Rita recalls, "The doctors said, '*We have news. It's HIV.'* First, I'm not sure what happened. I think I was in shock. I asked, 'Do you have any medication for me?' The doctors said, 'Of course. Don't worry.' Then I started to scream. I first thought of my partner. We have been together now for 15 years. I thought of him first. I thought - did I give it to him? Then I thought - *am I going to die?* You see back home in Africa if you get HIV, that's it. You're dead."

I sit with Rita as she continues to share her experiences about the 2-month period she spent in the hospital, recovering from the stroke caused by the HIV virus.  She was already in the AIDS stage of her HIV illness at the time of her stroke.  Rita says, “My CD4 count was 17.”

“Seventeen!”  I say to Rita in disbelief.  It’s overwhelming to hear her story.  I can’t imagine what that time in Rita’s life must have been like for her: very difficult physically and emotionally, I think to myself.

“Yes, 17.  *It’s not easy*.”  I can feel how difficult it must have been for her. Hearing Rita say these three words seems to bring heavy emotion for Rita.

“It wasn’t easy.  I was really ill in the hospital.  I almost died.  I kept saying to my partner, ‘*Please let me go.  Please.  Let me go.  I don’t want to live. I am [too] tired to live.*’ And my partner would say, ‘You are selfish.  Think about us.  Think about your kids.’”  I sense that Rita’s partner was trying to be supportive and emotionally strong for Rita and trying to encourage her to stay hopeful.  I sense that her partner was determined to see Rita live through this experience and to live with HIV.

Rita continues her story: “It wasn’t easy.  My kids – when they came, I was sick.  I ended up in the hospital the week they arrived and I was not there to give them direction.  Every single day I was crying.  *It wasn’t easy*.  And my father . . . I believe he was ashamed of me and . . . he is still ashamed of me.  My father was there in the hospital when I was there.  I’m his first born and he was worried about me.  But he wanted me to keep quiet about it – about my HIV – not to tell anyone.  One time he came to the hospital and he saw that I was reading a book about HIV.

He said, ‘What’s going on? What are you doing with this book?’

I said, ‘I just want to learn about HIV.’

My father said, ‘How about if someone comes and sees you reading this HIV book?’

I said, ‘It’s okay – I am the one who is sick. I’m the one living with it.’ That was the last time I saw my father. I called him a couple of weeks after that happened.

I said, ‘What happened? Where are you?’

He said, ‘I was a respectable person until you . . . I was a respected person in our community. Not anymore because of you.’

That’s the last time I talked to my father . . . since I was in the hospital. That’s it. About eight years since we last spoke. It wasn’t easy. It’s as if I am a bad person or something that I got the disease. It was difficult. Still . . . it is difficult for me that my father does not talk to me.”

I think about how difficult it must have been for Rita to be rejected and emotionally abandoned by her father. Rita tells me many times how much she loves her father despite his rejection of her and her HIV illness. I think of her father’s words, ‘*Because of you’*. I can’t forget the words Rita’s father spoke to her and that he feels his daughter brought shame to him because of her illness. ‘*Because of you*’, Rita’s father used these words to blame Rita for bringing shame to their family. I think about my own children. I can only imagine the difficulty of feeling isolated from your parent at a difficult time, such as being diagnosed with a serious illness. How painful this must be for Rita. This was a time when she needed family the most. Her own father, whom she loves so much, left her. Later that evening, I write in my field journal:

*I feel very sympathetic towards Rita as she talks about how her father has rejected her and blames her for bringing shame to the family. The concept of bringing shame to the family is one that I still try to understand today, for in my family and culture – there is a strong belief that one must do everything to not bring shame to the family – whether it's not finishing school, having a child out of wedlock, getting into trouble with the law, being gay, having the wrong friends, and so forth. I have lived my entire childhood and young adult hood life following these unwritten rules about behaving in ways to avoid bringing shame to the family. Because of this Rita's stories of her father resonate with me. I feel a great amount of sympathy for Rita – I understand the pain that comes along with family members pushing you out of the family for a reason that doesn't seem justifiable. I wonder how the love between a parent and child becomes broken. Is there is a lack of understanding of each other? Perhaps Rita's father doesn't understand Rita; or perhaps he doesn't understand HIV. I wonder what kind of meaning Rita's father attaches to HIV that he feels that she has brought shame to him and his family after her diagnosis.*

### HIV illness and its impact on family relationships.

Over time, I get to know Rita and through her stories, I also get to know some of the important people in her life: her partner, her father, her children and her community. Rita's story of living with HIV is incredible to me. What strikes me most is Rita's experience of pain and hurt as a result of her HIV illness – the physical pain and hurt, but also the emotional pain and hurt she experienced in her relationships with those around her. I learn from Rita that her relationships with her partner and some of her friends have healed; but that her relationships with some of her family members are broken. How painful it must be, I think to myself, to have some of your family leave you because of an illness that bears so much stigma. How troubling that some people believe that HIV is a disease of immorality and shame. How painful to be rejected by a parent whom you love so much, because they feel that you have brought shame to the family. As I listen to Rita, I wonder how Rita reconciles her experiences. How does she move forward and remain connected to her family story? How will this experience shape her future and also her own children's lives?

### *Rita's children - "If I wasn't sick, I could have guided them better."*

Why[7]
I'm in a new country
It's cold here
It's not warm like back home.
I don't understand what people around here are saying.
I don't speak their language.
What are they saying?
I want to be with my Mom.
Why is she sick?
AIDS?

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[7] This poem was created, based on narratives that Rita told: the story of what her children experienced at the time of their arrival in Canada and when Rita was diagnosed with HIV and AIDS. This poem was written from the perspective of her children.

She's dying!
Why must my Mom be in the hospital so long?
Why can't she talk?
Why can't she walk?
Why is she so sick?
I want my Mom!
I want to bring her home!

Rita tells me about her experience with her children during her time in the hospital when she was diagnosed with HIV. During this conversation I feel complete sadness for her children and for Rita as well. As a mother, I can imagine the pain of seeing your child hurt or suffer. I imagine it would be very difficult to see your child suffer from something that hurts them. As Rita tells me the story of her children during the time of her AIDS diagnosis in 2003, I can hardly imagine the feelings that her children must have experienced at that time. But I also imagine the pain and hurt that Rita must have also experienced. While Rita was in the hospital recovering from her AIDS-related stroke, her daughter attempted suicide. At only 16 years of age, her daughter felt so overwhelmed with life that she attempted to take her own. Rita shares these moments from what she can recall, but she also remembers through the stories told to her by her partner and daughter in previous years.

"My daughter tried to commit suicide when I was in the hospital. When I had my stroke and when I was diagnosed with HIV, she tried to commit suicide. It was very difficult for her and my son . . . Culture shock, they didn't know anyone, and they didn't speak any English. It was very hard for them. My partner was very supportive and everything to them, but it was really hard still for them."

Rita continues, "When my daughter tried to commit suicide, she too ended up in the hospital. I think she took pills because they tried to wash her stomach. *I cried* . . . My daughter thought I was going to die when she knew I had HIV. You know, my kids – we are from Africa, from Ethiopia. If someone is HIV positive, it means they will die. There's no surviving. My kids thought I was going to die. *It was a mess*. The social workers took my daughter from the house and they put her in their care. My daughter ended up at the hospital . . . *It was a mess* . . . *It was a mess*. Then after her hospital stay, my daughter was taken into care – like a foster home. It was really hard for her at that time. *It wasn't easy*. The social workers at the time said that I couldn't contact my daughter. They said that because of me, my daughter wanted to kill herself. They thought it was a good idea at that time for us to be separated. My son too – it was hard for him. He was mad at the doctors. He was so scared – he thought I was going to die. I remember him fighting with and screaming at the doctors 'What are you doing to my Mom! You are killing her! I want to take my Mom back home – I don't want her to die here!' . . . He ended up in trouble, drugs, alcohol and everything. Even today, my son is still troubled."

Rita pauses for a moment then continues, "I keep thinking – If I wasn't sick . . . If I didn't end up in hospital, maybe I could have guided them better and helped them adjust to their life in Canada. But I wasn't there for them . . . *I wasn't there for them*."

At that moment, there was a brief silence between Rita and me. As a mother, I felt her pain and regret. Rita still carries regret for not being able to be present physically and emotionally for her children when they arrived in Canada. Her children came to Canada to be with their mother, only to be separated from Rita by her illness. The news of her HIV illness and the timing of her diagnosis was an intense combination of life events for Rita, her daughter and her son. As Rita and I sit in silence, I can sense the '*what if*' between us. I can feel the regret Rita felt during that time in her life. I know she would have done everything for her children if she wasn't ill. In my heart, it would not be right to ask Rita *'what if-'* for it would not change anything that had already happened in her life and the life of her children. Perhaps, it would only bring more regret and pain. I look at Rita and I see the sadness in her eyes. I do not need to ask, I can see what this experience has meant for to Rita. I can see the sadness in Rita's dark eyes and we continue to sit quietly together.

Rita tells me that over the years, since her children's arrival in Canada, her relationship with her children has evolved in a way that Rita was not comfortable with. Rita says, "Well, they were very young when they came to Canada and it was a very bad age, you know what I mean? Like my son, he doesn't want to go to school and he went with a bad crowd of friends. He started to drink and use drugs . . . I don't know. It's like they forgot where they came from, especially my son. I was kind of disappointed. You know, they didn't grow up with me, they didn't know me that well. They didn't know I was their mother. They grew up with their dad and the grandparents on their dad's side . . . I think that's why it wasn't easy for them. It was a new country for them, I was sick and we were trying to get to know each other. I was trying to be their mother, but it was a mess . . . *It was a mess*."

Rita continues talking about the relationship with her children in present time. "With my son, I don't know . . . He's still in trouble. I'm not happy with him so I've had to draw the line with him and I said to him, 'Unless you are straight with your life, please don't try to talk to me or come in my house.' If he calls and he is drunk, I will not talk to him. If he is not drunk, then I will talk to him. I believe he went through culture shock. When he came to Canada, I was sick and then he started to get involved with drugs and he was even in prison. He didn't want to go to school . . . I was in the hospital when they came to Canada and there was no one to show them direction in life. It was my dream, you know, that they go to school . . . but I was so sick that time. Before, I used to say it was my fault . . . now, I accept that it is not my fault anymore because he is not a kid anymore. I tell him all the time that until he is sober, no drugs . . . to not come to me. I love him and I know he loves me."

Rita tells me about her daughter. She says, "My daughter, she is good - she has her own family now. She has a son who is 2 years old now. I was babysitting her son and it was amazing! Now he mainly goes to daycare." Rita's eyes light up when she talks about her grandson, but then her eyes look down and she continues, “But now my daughter is close to my dad, her grandfather . . . yes, and she always takes his side. Like before I would talk to my son and daughter and say things like, ‘Be careful with people. Look at me, I’m sick. You have to watch who you sleep with. Make sure you use condoms- that type of thing. But my daughter, it was hard. She would say something like, ‘You did it to yourself, so it’s none of my business.’” At that, my heart sank for Rita. Not only did she experience rejection from her father, but now from her daughter, with whom she hoped to have a good relationship with.

“I remember talking to my daughter one time about the time she tried to commit suicide and was taken away from our home. I said, ‘I’m sorry. I can’t help it, I can’t take it back. I was sick. I’m sorry I wasn’t there for you when you tried to commit suicide. I wasn’t even allowed to see you in the hospital.’” I wonder if Rita’s daughter carried too much pain over the years that has complicated Rita’s relationship with her daughter: being separated for many years following birth, learning about their relationship as mother and daughter, coping with Rita’s HIV illness, coping with settlement in a new country, and seeing the strained relationship between Rita and her father. I still wonder how these early stories of arriving in Canada have shaped both Rita and her daughter.

“It’s like she didn’t care too much . . . we didn’t click, we started to fight. I was told that when I was sick in the hospital, I said some hurtful things to her – that I was afraid to see her . . . I don’t know why I said those things, they said it was because of my stroke, I was confused. But I've said to my daughter, 'I'm sorry. I wasn't there for you. Give me another chance to be your mom.' So we tried and we were okay . . . we were okay. When she had her baby I was looking after her son about a few years ago . . . Yes, I was so happy. When my daughter went back to work, I was watching my grandson and I was like, 'Okay – now I am living!' Watching him gave me hope again . . . But all of a sudden, one day, she just changed. I don't know what happened. All of a sudden she took the baby from me and said, 'I don't want to see you anymore.' I believe that my dad has influenced my daughter."

It's been about a year since Rita last saw her grandson. He is 3 years old now. Rita tells me about a time when she last spoke to her grandson over the telephone. Rita's partner happened to see her grandson one day and he dialed Rita on his mobile phone so that Rita could have a conversation with her grandson:

"Are you my grandmother?" said the little boy.

"I hope so," said Rita.

"How come I have a White grandma and a Brown grandma?" the little boy said, confused.

"Are you my grandma?" the little boy asked again.

"I hope so," Rita said again.

"Is that the Brown one?" the little boy said in the background as he let go of the phone.

Rita tells me how hurt she felt after this conversation with her grandson. At that time, her partner tried to facilitate a visit between Rita and her grandson, and Rita explains to me, “I said I didn’t want to see them again . . . because I know my daughter, she will take my grandson away again once I see him, and that will hurt again. I cried for days after that. I didn’t want to go that route anymore, of getting hurt again.” Rita looks down at the table as she tells me this and at that moment, I feel an overwhelming sadness for Rita and for the pain that she has experienced within her family. That evening, I write in my field journal:

*I think about my time with Rita today and I feel very sad for her. How much rejection can a person take from her own family? I’ve seen too much of it in my own family; I’ve experienced it myself and it took me years to try and understand it – why people reject others, how to cope with rejection and feelings of isolation. It’s complex and is so deeply rooted in people’s pride and anger. I wanted to reach out to Rita earlier and tell her it was ok; things were going to be ok. But for some reason, I couldn’t because it just didn’t feel like the right way to provide comfort or the right thing to say. For I know, that feeling rejected and isolated in one’s family is not okay. It’s not easy. What felt right this afternoon with Rita was that I sit with her, and gave her the space to share her stories, her pain and hurt, while I sat quietly, listening to her. I felt her pain and it saddens me to think that her daughter has also separated herself from Rita . . . As I write and reflect, I look over to the left of my computer screen. A prose is posted beside my computer screen and I look at it often, when I feel like peace has been* *disrupted in my life or when I witness sadness or unhappiness in those around me. I read it to remind me of the things that can help bring peace in my life and the lives of those around me; it is a religious quote that emphasizes that Jesus loves and trusts us always and that we should try to live by that example: of love, kindness and respect towards others.*

*If only life was as easy as living by these simple ways. But it isn't. I wish so much for Rita that one day she finds peace within herself and with her family, especially her children. It makes my heart ache that Rita, who still loves her children very much, experiences so much pain and hurt from the broken relationships she has with them. I wonder if there will be a day when Rita's children will understand her and the love their mother has for them.*

#### ***Rita's longtime partner – "I didn't want to hurt him."***

Over time, I learn about the relationship Rita has with her longtime partner and how her HIV illness has affected their relationship. They are still together today, despite the challenges that they both faced since Rita's HIV diagnosis. As I listen to Rita's stories about her relationships in her life, my empathy grows for her. Rita tells me about her relationship with her longtime partner, Ezra, from the time they met, to when she was diagnosed with HIV, to present time. Rita and Ezra met in 1997 and have been together since then. They never married however I always sense the deepness of their love and commitment to each other through stories told by Rita. Ezra came to Canada from Ethiopia as a young man in 1984, worked in Canada, and completed a graduate degree in eastern Canada. They met while working together in a small town. Rita shares with me stories about her relationship with Ezra, at the time of her diagnosis and the years that followed.

“When I told my partner that I had HIV, he didn’t say anything. He just left the hospital and I started to cry. I cried because he just left and I thought that it was the end of our relationship . . . I thought that he wasn’t coming back. But then he came back the next day. I think he thought more about my HIV. I said to Ezra, ‘We need to talk. You must get tested and hopefully it will be negative.’ When Ezra’s HIV test came back negative I was so happy! It was negative. But then I told Ezra, ‘We need to talk about us. I cannot be your girlfriend anymore. I don’t want to be your girlfriend anymore. I know you are not going to be comfortable with me anymore. You’re not going to be . . . I love you so much but I can’t risk hurting you and our relationship. Can we be friends?’”

Rita pauses for a moment then continues, “In my mind, I just thought I was going to die from the HIV. I thought I was dying from HIV. I couldn’t think about anything else except that I was going to die and I didn’t want to hurt Ezra. But then Ezra was so angry with me. He said, ‘You are selfish Rita. I am right here. I am here with you. But you say you don’t want to be with me! I am here!’ At that time, I really didn’t know much or understand HIV very well. I just knew that it would be hard for someone to be comfortable with someone else living with HIV – like living together, not just sleeping together in the same room. I really didn’t know much about HIV at that time when I found out – you know like could I give it to someone by shaking their hand, hugging someone, giving someone a kiss, and things like that . . . I cried many times. I knew I loved him; I just didn't know that he loved me that much to stay."

As I listened to Rita, I stayed silent often and felt overwhelmed by her experiences. I wonder how complicated life could get with a diagnosis of HIV. How do people negotiate their relationships? What does love mean in these moments? And as I wondered about Rita's personal relationships, I too wondered about my professional obligations and responsibilities as a nurse. Rita continued "I know today I am very blessed to have a partner like Ezra. Together, we learned about HIV. We asked our doctors and social workers questions about HIV. Ezra was willing to learn with me. We learned about how to live together and how to make sure we are safe in our relationship. He was so patient with me. I was always pushing him away at first. I would say things like, 'Leave me alone! I don't want to talk to you!' . . . Even though I didn't mean it. But he was very understanding. He met with the social workers at the clinic and he learned about understanding where I was coming from emotionally. We have been together for 15 years. He is still with me. I was really hard on him at first when I was diagnosed with HIV . . . I didn't want to be hurt if he decided to leave me because I am HIV positive. That's why I kept pushing him away. Even when I first got home from the hospital – we came home and I didn't want to be with him. I wanted to be left alone. I would go to the bedroom and I would close the door . . . I didn't want to see him, I didn't want to eat with him, I didn't want to sleep next to him. I love him to death, but I didn't want to be hurt by another thing: my daughter tried to commit suicide, my dad was angry with me and wasn't talking to me, I couldn't work, there was stress about our bills . . . and on top of this, I was very sure Ezra was going to leave me. I felt like I didn't deserve him. I was afraid to be hurt by something else. My life was a mess."

As Rita recalls this time in her life, I sense Rita's pain trying to cope with her diagnosis, to live with the changes in her relationship with her family members, and to understand what might happen to her relationship with her partner.

Rita says, "It took a couple of years before I felt like Ezra and I were going to be okay. I am lucky. I am very blessed. Even our relationship, our intimacy . . . it was hard in the beginning. Sometimes I felt like he was just being nice to me. Sometimes I would ask him, 'Why are you doing this? Are you doing this to make me feel better?' It took a long time for us – for me to accept that Ezra really loved me. And he is very accepting of the changes in our life . . . we learned how to be safe during intimacy. It was scary . . . it was scary. We are very safe but Ezra still has to be tested for HIV every 6 months because we have been together for a very long time. So far, his tests are negative."

As Rita tells me this, I catch myself breathing a quiet sigh of relief. I think momentarily, what Rita's life would be like if she learned that her longtime partner also tested positive for HIV. I quickly remove that thought from my mind and I quietly give thanks that her partner has tested negative; this sense of relief and thanks has been shaped by listening to Rita and I have learned alongside her, just how complex and challenging living with HIV becomes.

Rita continues, “All this time - all this time, Ezra has been with me. Sometimes I just can’t believe that he has been with me all this time . . . I wonder sometimes what I would have done if he wasn’t there. I love him very much. It’s been very hard . . . I love him. And the funny thing is that he will tell you that he is the lucky one in our relationship,” Rita says quietly and humbly.

Rita tells me that over the years, her partner has been the greatest support to her since her diagnosis with HIV. Ezra has been present at Rita’s medical appointments and appointments related to her illness. He understands the neurological impacts of the stroke that Rita had. For example, he understands her seizures and has learned what to do if Rita has a seizure at home or in a public place; he understands her medications, their side effects and timing of doses. I also learn that Ezra is not only supportive in managing Rita’s HIV illness, but also supportive of Rita’s involvement in the HIV community and in their local Ethiopian community. He is also supportive of Rita’s participation in several research studies. I wonder how both Rita and Ezra decided together to participate in studies and in community work talking about HIV and prevention in their local community? I wonder what their work in the community means for Rita and for Ezra individually and as a couple. Rita has mentioned before that there is still much stigma and misunderstandings about HIV in their local community. This is evident in her father's rejection of Rita because of HIV and the work she does in the community.

Together, Rita and Ezra are participating in a study about HIV discordant couples. Rita says, "I am blessed . . . I am blessed. He's a very good person. He is a very, very supportive person. Even when I was having many side effects of the medications, like my memory became poor – he always reminded me to take my medications. Even if he is not home, he will call me and ask if I have taken my medications. Ezra is always there for me. When I'm down, he will say, 'You are strong. You are doing good. You are healthy and happy – we are together.' He gives me a boost of strength, even though it's not easy for me sometimes." I eventually learn that Rita and her partner feel the importance of giving back to the community, especially in the area of HIV prevention and education. Rita describes how there is much work to be done to prevent the spread of HIV in her community and that the first step in doing so is creating an awareness and understanding of what HIV is.

One afternoon, Rita tells me how Ezra's family has reacted to her illness. Since Ezra and Rita have been together, Rita has become very close to Ezra's family, like they were her own family. She developed close relationships with Ezra's father, brothers and sister over the years. For nearly 10 years, Rita sent some of her earnings to Ezra's family in Ethiopia to help support them. Ezra and Rita even sent one of his brothers to university. Rita tells me that she is the one who told Ezra's family about her HIV illness. One time during a visit to Ethiopia to visit family, Ezra’s siblings and his father took him out for dinner. Rita says, “They said to Ezra, ‘Let’s have dinner. We want to talk to you.’ Ezra said, ‘What do you want to talk about?’ They said, ‘We want you to be separated from Rita. We know she’s HIV positive. We don’t want you to be with her.’ Ezra didn’t say anything to them at that moment. He just called the waiter in the restaurant and asked for a red pen and paper. So the waiter brought the red pen and paper. Ezra took the red pen and drew a line on the paper and Ezra said to his family, ‘Don’t cross this line.’ Ezra’s father apologized. But you know . . . I don’t blame Ezra’s father for his concerns. He didn’t know or understand that people can live together when one gets HIV.”

“Wow,” I say to Rita. I can’t find the words to express how struck I am by Rita’s story. I admire Ezra for his ability to stand by his partner, despite his family asking that he separate from Rita because of her HIV. I am also struck by Rita’s reaction to her father-in-law. Rita did not become angry at her father-in-law; rather, she showed compassion and understanding towards him and his concern for his son, Ezra. That evening, I write in my field journal:

*When Rita told me that Ezra’s family tried to talk him into leaving Rita because of her HIV, I was lost for words. His reaction to his family was bold and demonstrated his love for Rita. It seems like other members of Rita’s family have fallen easily into anger and blaming Rita for her HIV illness, or for bringing shame to the family. However, Ezra stood by Rita and did not fall into anger or the trap of blaming Rita for her HIV illness. The other part of Rita’s story that* *struck me was how she responded to the attitude and behavior of Ezra's family. "I don't blame them," Rita said. What I see in Rita and Ezra is a couple who are deeply committed to each other and who are full of strength and grace – not an aesthetic grace, but a spiritual grace of kindness towards each other and others, despite the challenges they have faced with their families since Rita's HIV diagnosis.*

### ***Rita's father – "Apapa, I love you."***[8]

One afternoon, Rita tells me about her relationship with her father and her Anglo-Canadian step-mother. Rita says, "My dad has been with my step-mother for a long time now. When I came from Ethiopia, I stayed with them for 4 months because my step-mother had an old mother. Her mom was very old and she was sick. So I was the one taking care of her. While I took care of her, I still had lots of dreams in my mind . . . you know, come to Canada, work, bring my kids . . . I wasn't comfortable living with them. They didn't pay me. I just took care of the mother, ate, and slept. It was okay. I was okay to help my dad. But I had dreams. So I found a friend of mine, a family friend who was working in a hotel in a small town in Alberta. Our family friend told me that there was a job opening at her work and that I should apply, so I did. The hotel sent me a letter saying they accepted my application. When I told my dad about my new job, he said, 'Where is this letter they gave you?' I showed it to him and he took the paper and he threw it in the garbage. This happened the first month I was in

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[8] Apapa, in the Ethiopian language means 'Daddy'.

Canada. He didn't want me to work for the hotel because I was taking care of the old mother. There was no one else to take care of her. My dad was working. My step-mother was working. So yes, I had to stay home and take care of the old mother. She was a very good person, the old mother . . . But then, I got another job offer and this time I didn't show my dad the letter. I said to myself, *I'm going*. So the next day after I got my letter, I left and they put the old mother in a nursing home. My dad was very mad at me because I left home to work. It was about a year that he didn't talk to me. But then we talked again after about a year." Rita tells me that she didn't mind helping her father and step-mother with the care of an elderly family member, but at the same time, wanted to live her dream of working in Canada and earning money to bring her children to Canada.

Rita and I re-visit the story of her dad's reaction to her HIV illness. To this day, he still does not want to have any contact with Rita not only because of her illness, but also because she is also very open about her illness in her community. Despite her father's rejection, Rita tells me that she still tries to make contact with her dad. Rita says, "I tried calling my dad once again and his wife, my step-mother answered:

> 'Hi, can I talk to my dad please?' I said.
>
> 'You know he doesn't want to talk to you. You shouldn't even call to ask,' she said.
>
> 'Can you please tell him that I don't know what I did, but that I am sorry. I just want to say I'm sorry and that I want to be friends again,' I said."

Rita looks down as she recalls this moment. I feel sad for Rita as she tells me about the last time she tried to reach her father, whom she loves very much. It's difficult to feel rejected by others; it must be even more difficult to be rejected by your parent. Over time, I learn about how Rita feels towards her father and how hurt she feels that he has shut her away from his life. Rita frequently talks about how grateful she feels towards her father and how much she loves him. She frequently described this gratefulness in relation to her HIV illness; if her father didn't bring her to Canada, Rita feels she would not be as well as she is today with her HIV illness. Despite the strained relationship Rita has with her father, she continues to reach out to him.

Rita says, "It's my dream . . . I want to see him again and tell him - look him in the eyes and tell him how much I love him; how thankful I am for bringing me to Canada. It's my dream to do this . . . He doesn't want to have anything to do with me," Rita says quietly while looking away from me. "Sometimes on Father's Day I call him. He never answers his phone, but I always leave a message, even though he never calls me back. I would say, 'Apapa, I love you. Thank you for bringing me to this country. If you didn't bring me to this country I would not be alive today.' I love my Apapa very much. I've cried many times because he does not want to talk to me or see me. He just doesn't want anything to do with me anymore because I brought him shame. It's because of my HIV." And Rita's dark eyes fill with a certain sadness that I hadn't seen before. I feel sad for Rita, that her father doesn't understand Rita's hurt from their estranged relationship. I am saddened even more for the way Rita's relationship with her dad has also affected her relationship with her daughter. In my field journal, I write:

*I feel much sadness for Rita and the broken relationship she has with her father. Since we've met, I've learned how much Rita loves her father through her stories, her words and even through the look in her eyes when she talks about him. She lights up when she talks about how she first met her dad and how he brought her to Canada; she looks sad when she talks about how their relationship changed after she was diagnosed with HIV. I feel sad that Rita's father blames her for bringing shame to him and the family because of her HIV illness. I wish so much that he would understand Rita and understand the illness as something that is not shameful or immoral. Rita talked about how upset he becomes when she does work in the community, bringing messages of education and prevention to her community. I think it is so sad that his love and acceptance of his daughter is clouded by his beliefs about HIV. I think about what might have shaped his beliefs – his cultural, religious, and moral viewpoints?*

*Since her diagnosis, Rita continues to try and reach out to her father. He never picks up the phone when she calls him; he never returns her messages when she leaves them. I imagine the hurt and pain that Rita experiences from this. I admire her for her grace; her patience; her persistence; and her love of her father, despite his feelings towards her. I wonder what Rita's father feels in his heart towards Rita . . . When I listened to Rita's stories of how they first met and* *how he reached out to Rita and brought her to Canada to be together, I don't doubt that he loves her very much. But what is it about 'HIV' that has made him turn Rita, his own daughter, away?*

### HIV illness and its impact on Rita's life.

Listening to Rita's stories and experiences of living with HIV has made me feel much compassion and respect for Rita – for all that she has experienced living with HIV, for all her hopes, for her sorrows, for her attempts to make the most of each day she is given and for all she has done in the HIV community. Over time I learn about the significant impacts that her HIV illness has made in her life. Many times, Rita talks about her Catholic faith, the physical changes in her body, changes she has had to make in her life, and her desire to give back to others. What follows are some narratives weaving through her experience of living with HIV.

#### *Faith and spirituality – "Why did you do this to me, God?"*

Very early in our relationship, I learn that Rita is a devout Catholic. This is interesting to me, as I too have been strongly shaped by the Christian faith. As Rita and I sit together and understand that we each are shaped by similar beliefs, I realize that she has experienced many burdens in life and yet has still been able to live the best way she can, despite these burdens.

In the years after her diagnosis, Rita describes the difficulty she had accepting her HIV illness. She says, "I remember I kept saying and thinking – this is it. It's not about HIV. I did something wrong and this is it. This is why I have HIV. Today, I don't feel the same way. It's changed. But before when I was first diagnosed, it was very hard. I didn't even want to see my face in the mirror. I felt like people will know – like it's written on my forehead or something – that I did something wrong. It took me a long time to not think that. It wasn't easy."

Rita continues, "I believe in God and that helps me a lot. There have been many times when I feel depressed and I feel like maybe I am a bad person; that I got HIV because I am a bad person. But I don't know – I think of God and I believe in him and I know I am not a bad person. It's not easy living with HIV. Trust me, *it's not*. Sometimes, I think about not taking my medications. When I take my medications, there are so many terrible side effects. I know I'm not going to get cured with these medications so I think about not taking them. But I will look at the cross hanging in my living room – I will look at it and say:

'*You suffered for me so I may go to heaven. Please forgive me.'*"

Rita continues, "I couldn't think about my life without God. Even for a second, I couldn't imagine my life without God – I don't think I would have my life without God; there is no life without God. When I was in the hospital in 2003, I was mad at God. I would say:

*'Why me? I pray . . . I go to Church . . . why did you do this to me, God?'*

I even felt like I was being punished for something. But I know God doesn't punish people. Back in Africa, HIV is like a curse. People think you get HIV because God is punishing you. So I felt like I was being punished. I think I am okay now. I'm doing good with the medications. But it is him who is working and helping me. God works in his mysterious ways. It took me a long time to realize he is not punishing me and to say:

*'I'm sorry God, it's not you who gave this to me.'*

"I know that I am okay; that *I will be* okay. I don't blame God anymore. I still blame myself. It is hard. Sometimes I have to blame someone. But I don't have anyone to blame but *myself . . . it's my fault*. I cannot blame God – he didn't do this to me." I wonder how Rita sees the interplay between broader religious beliefs and access to condoms and sexual health education. How does she make sense of what we know are often conflicting interests? How do we reconcile care with a lack of access to resources, such as condoms, that might save lives at very little cost?

Rita continues, "I cannot blame my old boyfriend. He is dead now. Maybe he didn't even know he had HIV. When I came to Canada, my old boyfriend was sick. He started coughing; no one knew why he was sick. When I arrived in Canada, we still kept in touch – like a long distance type of relationship. My brother went home to Ethiopia to visit and he called me one day to tell me that my old boyfriend died. I asked what happened and he told me the family said he died from an accident. I didn't even think about HIV. I believed what the family said – that he died from an accident. But eventually I found out that they hid his HIV from everyone. My old boyfriend died from HIV. I wish I knew. I would have tested myself here in Canada . . . I still feel like I should have protected myself or I should have listened to my grandparents. I'm Catholic; I was supposed to listen when my grandparents said, *'Wait until you get married to have sex'*. I should have listened to my grandma. She loved me and she worried about me . . . *why didn't I listen to her?* . . . So I still try to forgive myself for that."

As Rita tells me about her relationship with God, I find myself thinking about Rita blaming herself for her HIV illness. Each time I meet with Rita, she never places blame on her previous boyfriend for getting HIV, but often blames herself for contracting HIV. It is difficult sometimes to hear Rita blame herself for her HIV illness for I have a sense of the burden of carrying self-blame and guilt. As I sit with Rita and hear her story, I understand where she is coming from when she talks about blaming herself. Years ago, I experienced a time period in my life where I carried similar feelings inside: feelings of guilt and feelings of being punished by God. Listening to Rita brings memories to my consciousness. Emotionally, I begin to remember how these feelings weighed heavily inside for me and I believe it caused much personal suffering. I wish so much that Rita did not have to carry this burden inside because each time I see her, I wonder if she quietly suffers. I do not want Rita to feel like I am judging her in any way. I want to show my care and that I continue to listen. Rita says, "I still have to forgive myself . . . it's very, very hard. It's not easy. Still today, I cannot forgive myself for getting HIV. I still feel like it's my fault. I wish I can forgive myself. I *want* to forgive myself."

“Rita,” I say, “It’s very gracious of you to not blame your past boyfriend. But I wish you would not blame yourself. Do you think you will ever forgive yourself?” I ask Rita, with care and with hope.

“I don’t know. I will keep trying. So far, no.” Rita continues, “My priest knows I’m HIV positive. But I have never talked to him about it more. I only told him so that he knows about my wishes when I die. I pray to God all the time. I talk straight to God, not my priest. It’s not easy. I’d love to talk to a priest, but it’s not easy . . . maybe they will judge me like my dad . . . I know I have to forgive myself. I ask God to help me forgive myself. I also pray for my kids. I don’t want them to experience the same thing as me. I believe you understand me.”

“Yes . . . Rita. I understand you, I’m Catholic too. I find when I have difficulty in understanding things in life or forgiving myself for some of the things in my life or learning to forgive others . . . I find talking to a priest is helpful – not to find answers to a problem, but to talk things through and to find some clarity around forgiveness,” I say to Rita. At this moment, I feel a different sense of connecting with Rita. I think often about Rita’s feelings about forgiveness and while I have come to understand forgiveness through being Catholic, I wonder what this means for Rita.

Rita says, “I can’t talk to my priest yet about how I feel. I see him every week, every Sunday. You know, I tried to go to an Adventist church and for some reason, it wasn’t good for me.” As Rita tells me how she sought comfort from another Christian, non-Catholic Church, I remember a time in my life when I too sought comfort and understanding in other Christian, non-Catholic Churches. During that time in my life, I experienced much confusion about the Catholic Church because some of its rules and traditions did not align with what I believed to be right and just. But I eventually went back to my Catholic Church after years of searching for a place of inner comfort; a sense of reconciliation between the principles that I wanted to live my life by and the rules of the Catholic Church. I was trying to find a sense of comfort between how I could live my life, face some of the rules of the church, and avoid potential judgment for perceived mistakes and wrongdoings. Rita continues, “It was very, very hard for me to go to another church.” And I quietly understand Rita. The Catholic Church for me was also very connected to my upbringing, my parents and my family. I eventually went back to the Catholic community because of the deeply rooted connection between being Catholic and belonging to my family.

I sense that Rita has wanted to talk to her priest for some time, but hasn’t felt comfortable in approaching him because of the fear of being judged by the priest she sees weekly. “Rita,” I say, “I have a friend who is a priest - only if you are interested . . . I can give you the name of a priest who would be more than happy to sit with you. If you are open to something like this – seeing someone who you would never really see again, just let me know and I would be happy to connect you with him.”

"Thank you," says Rita. "I would love to talk to him." Later that evening, I write in my field journal:

*Today, Rita and I talked a lot about her relationship with God. At one point, I worried if I had stepped out of my research boundaries. But I felt today that I wanted to be as real as I could be with Rita. I wanted to attend to her; to respond to her when it felt natural to. Because we are both from the same faith background, I felt like I could respond to her beyond being present as a researcher as she shared her stories with me. I wanted to relate as another person, even though I am reminded of my role as 'researcher' in our relationship. It was certainly a tension for me.*

*When I was with Rita earlier it brought so many thoughts to my mind as I listened to her stories about her relationship with God. Being with Rita also brought memories back to my conscience – memories from a time period in my life where I was struggling to accept my upbringing and belonging in the Catholic Church . . . There were many things I was struggling with as a Catholic: things like some of the Church's rules on same sex relationships, birth control, the idea of a punishing or angry God, and guilt associated with not following certain rules of the church . . . It's so interesting to me, that I connected with another person, Rita who also has experienced some of these tensions in her life– especially the guilt of not following certain rules.*

*When Rita talked about the guilt she experienced of perhaps doing something wrong or bad to have contracted HIV, I remember times in my life* *when I experienced guilt as a Catholic, questioning my Catholic faith. When I listened to Rita earlier about her worries of being judged by a priest, I wanted to say, 'Who would that priest be to judge and reject you?' I wanted to lift this burden for Rita, the burden of fear; the fear of being judged and rejected by her parish priest, by her Church community; and the burden to of carrying guilt for so long about 'getting' HIV. From what Rita shared, she has carried so many burdens for years . . . I think about how this guilt has affected Rita over the years since her diagnosis. It has certainly brought sadness at times; Rita talked about crying sometimes alone in her room. It brought blame towards God and in a way to herself; Rita would ask God, 'Why did you do this to me?' – which in a way speaks to a belief about a punishing God; that we are punished when we do something wrong. I also see how this guilt has affected the relationships she has with her family. It's awful to see that Rita's HIV illness has been connected to shame and blame. I believe this has deepened the guilt the Rita carries inside.*

*When Rita talked about realizing that God is not a punishing God, I understood a part of her journey. Being with Rita today reminded me of my own spiritual journey of discovering who God was. It took me years of trying to sort through messages I learned during my upbringing in a traditional Catholic family. It took me years to understand the faith I was raised in. I may not understand everything there is to know about the Catholic Church, but I've realized that there are two parts to the Catholic Church: the Catholic Church as an organization; and the Catholic Church as a community of people. I see that*

*Rita, through her own work in the community and service to others, lives out her life within the Church as a community of people.*

*At the end of our time together today, I felt like our relationship had deepened because of our common faith backgrounds and our ability to relate to one another.*

#### ***Neurological impacts of HIV –"My seizures are the worst thing I live with."***

Rita's stories of living with HIV are often intertwined with stories of her seizures and headaches. The HIV virus has been known to cause neurological disorders in some people (Vivithanaporn et al., 2010). Rita has been involved in a research study that examines the neurological effects of HIV. She falls in the 25% of people living with HIV who experience some form of neurological disorder. Rita suffered a stroke in 2003, related to her HIV illness. More recently, she experiences reoccurring seizures, also related to her HIV illness.

Rita's experience of seizures reminds me of a book I read many years ago about a very young Hmong girl who migrated to the United States and who experienced terrible seizures. *The Spirit Catches You and You Fall Down* (Fadiman, 1997) was the title of the book and every time Rita talks about her experiences living with seizures, I think about the little Hmong girl whose body would be overcome by an unstoppable seizure – something that would just take over her body. Nothing could be done except to wait and let the seizure take its course. The young girl's family had no idea what was happening when the seizures first began.  They thought a spirit caught the young girl and would just send a quivering, violent quake through her.  I've never seen anyone have a seizure before me, but this book provided me with the most explicit images of what a seizure could be.  That's how I imagine Rita and her early experiences of seizures.

Rita says, "My seizures are the worst thing I live with since I was diagnosed.  The first time I had my seizure was about three years ago.  It was scary.  I was on the phone, I fell down, bit my tongue and I had no idea what happened to me.  I was by myself.  It's like the phone was right there, a voice, but I was somewhere else.  I peed on myself . . . I had no idea what was happening to me.  My partner came home and there was glass on the floor, the table was moved and there I was . . . I had no idea what was happening.  At first, I would get seizures about five times a day.  Now, I've been taking medications regularly for it and it is controlled better.  But I still have a lesion on my brain – like scar tissue which is not healing.  It's not growing, but it's not going away.  So I still take my seizure medication on top of my HIV medications.  I have to go for regular tests like MRIs or EEGs[9].  They worry it might change into cancer.  But right now my doctor says I am okay.  My neurologist would like to do a biopsy of my brain to see if this lesion will turn into cancer.  But because they say there is a 50% survival from this kind of biopsy, I said 'No'.  I could become blind or paralyzed

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[9] MRI and EEG refer to diagnostic medical tests called magnetic resonance imaging and electroencephalography, respectively. In Rita's case these tests are regularly done to monitor abnormal tissue in her brain that resulted from her stroke.

from the biopsy . . . it wouldn't be the doctor's fault- it's just that it can happen. I don't want to be blind or paralyzed . . . it's scary."

Rita continues, "Sometimes I still have seizures. It's like I would be talking to someone and for a second or so then - *'Snap!'* I'm out and I will be back with you in a few seconds. One time we were having dinner with our friends. I didn't notice but my eyes were blinking. My partner noticed and he didn't touch me, he waited until I came back. My partner learned from my doctor that if I have a seizure, not to wake me . . . just wait until I am back from the seizure."

Rita says, "I have my dog and she helps me a lot. I call her Baby. My doctor suggested that I get a dog – she can sense my seizures."

"Oh really?" I say with surprise. I know pets can be therapeutic to people and people's wellbeing. But I had never heard of dogs being able to sense seizures before they happen. As Rita talks, I find myself thinking what it is like to not know your body and to rely on either those around you or on animals to let you know something is happening? What happens to our tacit knowing that something is going on?

Rita says, "Yes, Baby knows when a seizure is coming. I don't know how she knows, but she knows. When I am about to have a seizure, she runs and hides. She doesn't want to be near me. Even if I call her, she will not come to me and normally she is all over me. Even if I have a treat for her, she won't come if she senses something. So if I am cooking at the stove and Baby does this, I turn off the stove and I sit still. I wait and try to be ready. Sometimes I might sit on the floor."

One time, Rita cancels one of our meetings together because of a terrible headache. When we see each other again, Rita tells me that her headaches and seizures are the worst things she experiences with her HIV illness. Rita explains that often, she will get very bad headaches. The next time I see Rita, she tells me, "I will get bad headaches. They will last a few days - sometimes three days. They come two or three times a week. *Oh my God, it hurts!* It's very hard, it hurts right here -it's like fire here," Rita pats the side of her head.

Rita continues, "The HIV, my immune system, I am doing good. But the headaches, they're so painful that I can't sleep, I can't eat, I will stay in bed the whole day – sometimes the whole day and the whole night. Sometimes I will not sleep for 24 hours because of the pain. If I have a headache like that, I stay home. It's hard to explain, but for some reason, I know a seizure will be coming. My doctor even explained to me one time that when I have a headache, I should be prepared that a seizure can be on its way. When my headaches start, I will stay at home. I stay in my living room and I make sure that that I don't have anything near me, like a table. It's very painful. I don't even want to answer the telephone if it rings. I just need to be quiet. And my dog, Baby - she will run from me and hide under the bed. She knows it is coming; I *know* it is coming."

Although I have never experienced a seizure, I suffer from migraine headaches. Hearing Rita tell me about the pain related to her headaches makes me think about the pain I experience with my headaches. I’ve suffered from migraine headaches since I was a child. My headaches are debilitating. There are days when I cannot get out of bed or bear the quietest sounds, or the sight of light. In addition to the physical pain that my headaches bring, I cannot bear the emotional pain inside, the feeling of not being able to do anything – even to take care of my own children. I understand Rita when she tells me about her painful headaches; her need to be alone and quiet; and her need to be alone during this pain. I understand and know that pain very well.

#### ***Impact of HIV on everyday life – “I don’t want to feel like I am a disabled person.”***

During one of our meetings, Rita tells me more about her experiences of living with her headaches and seizures. The experience of seizures has affected Rita emotionally as well as physically. She describes the experience of her seizures and what this condition has meant for her and her life. She describes feelings of *feeling* disabled; the feeling of not able to do something or being told *not* to do every day things. To me, Rita seems like an incredibly strong, independent woman: from listening to her stories of coming to Canada, finding work on her own, bringing her children to Canada, and making her own choices in life; Rita seems like she is a very determined and strong-willed person. But I can only imagine what it must be like to have something, an illness, take away from the ability *to do*; the ability *to freely do* things in life.

Rita says, “I was a very hard worker before I was diagnosed with HIV. They called me ‘workaholic’!” Rita grins. “I was working three jobs – it was my dream. I came to Canada, I worked hard, I brought my kids here . . . I bought a house before I got sick. I did this all; I was strong. I even tried to go back to work after I was diagnosed. My supervisor was supportive. They gave me light duties, but I couldn’t do it. *I couldn’t do it*. Now, I feel like – what’s the point of my life? I can only live day by day. I’m not even allowed to drive. It’s okay . . . But *it wasn’t easy* to accept. It was very, *very* difficult for me. Not working, not driving – sometimes it’s the worst part. Last week, it was rush hour and I was standing on a street corner in downtown – I was on my way home from somewhere. I was watching people going to work, some of them coming from work . . . I started to cry . . . I wish I was like one of them, you know? I want to work too. I don’t want to feel like I am a disabled person or something. It hurts to think that I can’t work anymore. It’s still hard to accept that sometimes. Sometimes when I hear my friends tell me *‘I’m tired from work’* – I start to cry again. I miss it. It is hard. *It is hard*.”

Rita continues, “I miss driving too. I’m not allowed to drive. I asked my doctor last time if I can drive and he said ‘No’ and I accept that. I accept that it is not safe for me to drive. It’s scary to think that I can injure someone else. It’s not about me . . . I have to think about others. Why would I take a risk like that – hurting someone else? So, I cannot drive.”

When Rita tells me about how her illness has affected her life, I see the hurt and disappointment in her eyes. I look at Rita across from me and she looks tired and physically small and fragile under her bulky black coat. I imagine what Rita must have looked like years ago before her diagnosis. I imagine Rita, with the same dark tightly curled hair, but with eyes and a smile so bright with energy and will. At this moment, I look back at Rita as she tells me about her life now. I see how HIV has changed Rita's life over the years. It's affected Rita – her mind, her moods, her brain, her relationships, and her ability to live freely. It must be difficult to lose the freedom to do things in life. It must be difficult for something, like HIV, to take hold of your life and change your life as it has for Rita.

### *Finding purpose – "I want to try."*

I find Rita to be a remarkable person for several reasons. First, I believe she is very resilient. She has experienced much physical and emotional pain since her HIV diagnosis 9 years ago. Yet, she is able to take one day at a time, give thanks to God for each day she has and try to live her life the best way she can. Second, Rita is remarkable for her strength and humility. Despite the physical and emotional challenges she has experienced and lived through since her diagnosis, she has found meaning and purpose in her life by giving back to others. Her strength to give to others is remarkable. Her strength to reach out to her father who has shunned her is also remarkable. I admire Rita for her resilience, strength and humility.

One day, Rita tells me that she sometimes feels down. She says, “You know, when I see people, sometimes I say, ‘Oh yeah, I’m doing good.’ But deep inside, no. I’m okay, I’m lucky to be here, to be alive. But I live one day at a time. Sometimes, I will cry and cry. I just close my door and cry, cry, *cry*. My sadness comes out. But then when I am done, I am finished. I think about Ethiopia and where I am now in Canada. And I tell myself - I am okay, I am okay. I am alive.” And it’s at this moment that Rita shares with me that she has an adopted daughter in Ethiopia. Rita says, “In Ethiopia, there are kids who don’t have anything. I have a little girl, adopted, back home. She lost her mom because of HIV. She is HIV positive.”

I am in awe with Rita. I listen more to her story about her adopted daughter living in Ethiopia. She continues, “I was back home for my brother’s wedding and I went to visit Ezra’s family. This little girl was nearby. She was living near Ezra’s family. I overheard people talking about this little girl: ‘Oh, her mom died from HIV.’ I learned that nobody would play with this little girl. Parents of other kids would say ‘Don’t touch her, don’t play with her.’ . . . it wasn’t easy for this little girl. So I asked if I could see the little girl, if I could talk to her and play with her. Then I adopted her. She was only 4 years old. Now, she is 9 years old.”

Rita continues, “I call my little girl every Sunday. She lives with her grandmother. She is a good grandma. I send money to them so make sure she has medication, enough food to eat and a good education. If I know someone is going home to visit Ethiopia, I send clothing for my little girl and some other things.  I send her to a private school in Ethiopia.  I live for her.  Sometimes if I say to myself, I don't want to take my medications, I say – 'No, no, no – I have to live for her.' *I have to live*.  Her grandma has no income whatsoever.  So I have to live for her.  I call her every week, but I also call her when I am down.  You know when I feel like maybe I am a bad person that I have HIV . . . or I think that I will never be cured of HIV . . . or when I think about taking my medications for life with no cure . . . I feel down.  But when I hear her voice . . . She helps and God helps, of course."

Over the time that I spent with Rita, I learn that she volunteers in the community in various ways: she participates in several research studies; she volunteers as a peer support worker in the HIV community; and she participates in raising awareness about HIV in her local Ethiopian community.  I am moved by Rita's contribution of service in the community.  In addition to contributing to several research projects, Rita has volunteered many times as a peer support worker and as a voice to raise awareness in her local African community about HIV.  She has been a visible person in her community, advocating for education and awareness of HIV.  Sadly, this is the main reason why her father has rejected her.

One afternoon, I ask Rita about her work in the community and how she got involved.  Rita says, "People don't know the truth behind HIV – like people from my country.  It's a lack of education about HIV.  People only know what they hear from their family and friends, but they don’t know what is really going on . . . People, they think people who have HIV are bad people . . . very bad people. Things like – oh that girl, she sleeps around . . . that’s why she has HIV. You know, because women don’t drink, they don’t use drugs. So people say things like ‘Wow – look at her, she sleeps around and now she’s sinned because she has HIV.’ That’s why women hide. You know, people will say that the woman slept around and got HIV that way. But for men, it’s much easier . . . most people will think, oh the man, he has HIV, maybe he made a mistake. For the woman, it’s different. It’s very hard.

“When I was growing up HIV was hidden. No one was talking about it and when you start hearing about it, or you see people dying like every day, you just wonder what’s going on. People would die in neighborhoods. No one was talking about it, but people would start worrying about HIV. Like my old boyfriend. When he died, I didn’t know what was going on. I don’t think he knew what was going on too. I just remember when he was sick, he was coughing. But he never went to the doctor, we didn’t even think to go to the hospital to get checked. Even if people want to check for HIV, it’s not easy. Even though medication is free and available, you have to disclose your status. You can’t hide it . . . which is very hard. People back home would rather die than disclose their status. It’s hard. It’s the stigma.”

Rita continues, “Even here. In Canada, some of my friends – most of them are okay. Well, now they start to become comfortable around me. Before, some of my friends were not comfortable around me. Like even when we ate together, some them weren't comfortable to eat with me – that kind of thing. Some people don't understand yet. Many people here they still have misinformation and misunderstandings of HIV. Some people in my community think there is no HIV in Canada and then they have sex without any protection. *I can't keep quiet about it*. I have to say something. Deep inside, I have to . . . *I have to*. So this is why I start saying to people through our local radio program. I say it in our language – I talk about HIV." I am reminded of my earlier work alongside African communities; the ones I talk about in my narrative beginnings.

As Rita shares this with me, I am amazed by her strength and courage. She acknowledges the stigma and the misconceptions about HIV in her community. I am struck by the judgments made towards women living with HIV. Many people believe that if a woman gets HIV, she must have sinned or done something wrong by sleeping with multiple men; if a man gets HIV, he must have made a mistake, but is judged less harshly than a woman living with HIV would be. This double standard between men and women strikes me. What strikes me more is that Rita is willing to work against this stigma in her community in order to raise awareness among people. She knows what people will think about her. And yet – Rita has chosen to be a voice by trying to help people understand what HIV is. Rita's reason to be a voice in her community was simple: she felt that she just had to say something to help people in her community understand HIV and prevent the transmission of HIV.

Rita and I talk about the influence of her community work on her life. Rita says, “You know, this is why my dad doesn’t want to have anything to do with me. It’s not easy. Other people judge me too. I just try to say, ‘Oh forget them. I am okay – I can live without those people who judge.’ I’ve gained friends and I’ve lost friends. I just want to be treated like a friend, like for who I am. Those friends who have moved on – they think that I’m a bad person because I have HIV. Like if I have a woman friend, her husband or boyfriend will think I’m a bad influence. I usually have guy friends. But sometimes the women, they think I will do something bad. I don’t know . . . it’s a lack of education. It’s not easy sometimes. But Ezra, he is supportive of me. He gives me a boost. He is very supportive of me doing this in the community.”

Rita says, “I do interviews for radios and newspapers. It’s not for the fame or anything like that!” Rita laughs. “I just can’t keep quiet about people not knowing and understanding HIV. People have to know and understand. Every time I learn something about HIV, I like to share this with people – like through our radio program. We have an Ethiopian radio program and newspaper in the community and I talk about HIV there.”

Rita has also worked as a peer support worker, supporting people, mainly people from African countries, who are living with HIV in her community. Rita tells me that she decided to take a break from this work. She says, “I feel like Canada is the best. My medications are free, my doctors, the receptionist at the clinic, the nurses, the social workers, everybody . . . they treat me very good. I feel I owe something to Canada . . . I love this country. It's my way of giving back. It's not easy though. Sometimes I have to take a break from my peer support work because I hear from many people and their stories of being down. Some people have really hard lives and sometimes it's very hard to hear their stories . . . to hear people's stories sometimes . . . it's too much for me. One time, I was a peer support worker for 29 people and I couldn't take it anymore . . . so I took a break. Sometimes people would call me at 3 o'clock in the morning and one time, a person told me they wanted to kill themself. It's scary . . . it's hard for people. But it was a lot for me to take."

Rita continues, "You know, the social workers at the clinic gave me the idea to become a peer support worker. The social worker said, 'Rita, you will be good at it, you know . . . there's lots of people from Africa living with HIV, you can help them. If you help people, maybe you are helping yourself.' So I said, 'Okay, I want to try'. And I loved it. I met lots of people; I made lots of friends. You know, and I made lots of gay friends . . . I love them. I learned a lot from my gay friends, how to be nice and how to love others. They are my good friends."

"Rita, that is very giving of you," I say, "you know, to give yourself to support others living with HIV. I can see now what you mean when you say it was difficult." I am touched by Rita's service to others, despite her own physical health challenges; she has chosen to give to others through her work as a peer support worker. I admire Rita for this, but I also admire her for recognizing her need to take a break from this very emotionally demanding work. It is another demonstration of Rita's voice, strength and courage.

### Living with HIV – "I live one day at a time."

Rita would often say "I live one day at a time." Day by day- this is how Rita has lived her life for nearly 10 years. I am reminded of the journey that Rita describes each time we meet – the strength she finds in her faith and in God as she faces daily reminders of her HIV illness; not the HIV itself, but the different physical and emotional challenges that the HIV has brought to her life: the strained relationships within her family; the neurological effects of her HIV illness; and the need to come to terms with the reality that life with HIV is much different from the life Rita once had as an independent, "hard working" woman. At one of our last meetings together, we talk more about Rita's experience living with HIV.

Rita says, "Sometimes, I feel strong inside – like when I talk to others about my HIV. But sometimes, I'm not strong. To be honest, sometimes I will be at home, close the door and when I'm by myself, I will start to cry. I would cry. I would just cry and then I would have to say to myself – okay that's it. I have to try and live – one day at a time. I have to live for today. One day at a time – that's how I cope. I can hope, I try to hope for the future, but it is very hard to say that I will live long into the future. It's very hard to say how many months or how many weeks I'm going to live for. I just live for today; and then tomorrow is another day. Especially with my headaches . . . when I don't have my headaches, I’m okay. But when I have my headaches, it hurts so much and I feel like I can’t take the pain anymore. Every day is different for me – so I say ‘one day at a time’. Today is a beautiful day – I try to live each day the best way I can. I never know what could happen to me. It’s like when I had the stroke – it just came like that.” And Rita snaps her fingers at those words. At this moment, I find myself trying to understand Rita’s decision to live one day at a time. She has mentioned many times since we met that she cannot look ahead a month in her life or that she cannot make plans for her life too far into the future. I find myself thinking that Rita has lived like this for nearly 10 years since her diagnosis. Rita has talked previously about making long term plans for the future before her illness, including her hopes and dreams for her and her children.

“You know,” Rita says, “I was a very strong person and a very hard worker. I had three jobs at one point. I had everything – money, a house . . . But then the stroke- it changed everything!” Rita claps her hands together, in one loud clap. “All my life, everything turned from that point. I feel like something bad will happen anyway. So I don’t plan. I don’t think too much about the future. I just live for today – I feel like, why should I care about the future anymore? Something will happen anyway – just like my stroke. Ezra doesn’t like that I just live for today, each day. He often says to me ‘Don’t ever say that you will not live long – you might even live longer than me!’ Sometimes, he wants us to make plans for 5 years ahead, and I would just say, ‘Forget it . . . it’s too much for me to think 3 or 5 years ahead – even one year ahead is too much for me.' But every time June 23 comes – that's the day I got sick with the stroke and ended up in the hospital." Rita pauses then says, "Every time June 23 comes I feel like - Whoa! Another year! Whoa! Every time that day comes – I always think to myself – I never thought I would live another year! I never thought that I could live another day or even a week – let alone another year! June 23 is like my anniversary day or a birthday. I always remember what happened to me that day and every time June 23 comes, I thank God – I say, 'Thank you God, you gave me another year!'" Rita says happily. We laugh together as she tells me about what June 23 means to her.

Then I say, "Rita, June 23 . . . that is just over 9 years now."

Rita pauses then says, "Eight years, I believe." We pause as we both do a quick calculation in our head.

I say, "Rita, it is 9 years. It's just over 9 years. You will have lived 10 years next year in 2013." Suddenly, the mood shifts in the room.

Rita says, "Oh my God! Oh my God, *oh my God, oh my*!" And at that very moment, it was like a moment of realization for Rita that she has lived now for nearly 10 years. It is something that she couldn't imagine for herself before. And yet, Rita is entering into her tenth year of living with HIV. The mood shifts in the room and an incredible amount of joy suddenly fills the space around us. I see the happiness and brightness in Rita's eyes. A tingle of emotion touches my face as I look at Rita. I can see that she suddenly realizes how much time has passed since she was diagnosed with AIDS in 2003. I think Rita has lived day by day for so long that she lost track of the years that went by. She really believed that she would never live to the day when she could say, ‘It’s been almost ten years since I was diagnosed with HIV.’ It is an emotional moment for Rita and I feel happy to share this moment with her.

Rita laughingly says, “Whoa! I’m going to be 10 years! This is the first time that I realize that! God gave me 10 years! In 2003 when the doctor would tell me I would live for a long time, I didn’t believe him. I always left it to God to say how long I will live for – but I never, ever, *ever* thought about having 10 years!” And we sit for a while together as Rita smiles with disbelief, joy and happiness. She apologizes several times for laughing and smiling at the thought of living for 10 years since her diagnosis.

“There is no need to apologize,” I say to Rita. As I share this moment with Rita, we sit and enjoy this moment together – the moment of realizing that Rita has lived nearly ten years with her HIV; something that Rita has said over and over again – she would never live this long with her HIV.

I say to Rita, “This is something to celebrate.” She continues to smile at the thought of living nearly ten years with HIV. I light-heartedly say to Rita, “Maybe you can imagine a life with another 10 years ahead.”

Rita smiles and says, “Don’t push it!” She laughs and continues, “I think 10 years is enough . . . well, it’s up to God. He already gave me nearly ten years! I will go home today and light a candle and pray to God. Wow . . . I feel like . . . whoa it’s like I took these years for granted. Wow . . . 10 years! I have to call all my friends and tell them that I will be 10 years since my diagnosis. I just remember when I would talk to different people living with HIV – when they would talk about living for 10 or 15 years – I would just think – I would never reach that, that is just a dream for me. And now . . . *wow* . . . 10 years! I've had 10 years with my HIV!! God gave me 10 years! I never even thought I would live the next year. It's something to celebrate I think. God . . . he works in mysterious ways!" And Rita pauses for a moment. I can see that many thoughts are entering Rita's mind.

Rita continues, "I feel bad . . . it's like I lost time – blaming God, not praying at times, not caring or thinking about the future . . . sometimes I would just think – Why should I? I feel a little ashamed because sometimes I feel like I complain too much about my headaches or taking my medications. And I shouldn't complain . . . God gave me 10 years!"

At that moment, I say, "Rita, you shouldn't feel ashamed to complain. You're human! Every person has the right to feel their pain and to express their experience of pain, hurt or even happiness."

Rita says, "Maybe I can start planning in life – maybe just a couple of months ahead or 6 months . . . But not a year or more." Rita continues to smile with her thoughts. And at that, we sit a while longer together, celebrating the significance of Rita entering her tenth year of living with HIV.

## Closing Reflections

I will never forget the moment I shared with Rita when she realized that she has now lived nearly 10 years with her HIV. Her smile was so wide and bright; her eyes alive and open. It was at that point that I gained some understanding of Rita and her decision to live day by day for 10 years. By doing so, perhaps it was a way to make time pass quietly, not thinking too much about a future that seemed so uncertain. Rita experienced so much physical and emotional pain in the last 10 years since her HIV diagnosis. She continues to experience some of this pain today. Rita has said several times that she believed she would never be cured of HIV and now I understand why Rita chose to live one day at a time. Rita truly lost track of the years that passed, not knowing that nearly ten years have gone by as she lived each day in the present moment, not thinking about the future or her life ahead. That afternoon, when we shared that very important moment in Rita's life, we parted ways with a warm hug. I quietly thanked Rita for sharing her experiences with me and told her how happy I felt for her joy in realizing that it will soon be ten years since her diagnosis.

Rita and I spoke again over the phone in February 2013. I wanted to connect with her to see how she had been doing. I often thought about Rita over the months since our last meeting. I thought about how remarkable she is as a person: being open and courageous about her HIV illness, despite the emotional rejection she experiences with her father and children; her desire to be open about her HIV illness in her own community as a way to give back to her community –

to help create awareness in her community so that people can be aware of HIV transmission, prevention and testing; and her resiliency and strength as a person, despite the fact that Rita still feels she cannot forgive herself for contracting HIV from a former partner. When Rita and I spoke over the phone in February, I could feel her happiness and joy in her voice.

Rita said, “I’m sorry for not getting in touch with you sooner, Añiela. I’ve been busy making changes in our home. Since we met, it’s like I found meaning and purpose in my life again. It’s like I wanted to go out and do something again! So we are doing some small renovations in our home. And I am organizing a fundraiser for orphaned children in Ethiopia. I hope you can come!” At the sound of Rita’s voice, I smile and quietly feel happy to hear how Rita has been doing.

Rita continues, “The best thing, Añiela, is that I finally talked to my priest. Thank you, thank you for inspiring me and for giving me courage. I talked to my priest. I wasn’t afraid to anymore. I talked to him and it was good! He forgave me; and I forgave myself for getting HIV. I feel so happy now after I talked to my priest.”

As Rita tells me about her meeting with her priest, I remember the times that Rita used to talk about blaming herself for contracting HIV. I remember her talking about not being able to forgive herself for everything that has happened and how her HIV has hurt her family. Rita has wanted to talk to her priest for years, but felt afraid. I sensed the spiritual burden of her HIV illness during the time that I got to know Rita. She felt that her priest would also reject her for her HIV illness. Rita shared that her priest did not reject her, but helped with her spiritual healing and forgiveness. At that moment, I felt emotional; something that I couldn't name. I felt a shared happiness with Rita as we spoke over the phone. I was so happy to learn that some of Rita's spiritual burden had been lifted since we last met. As a human being, I find it difficult to see other people suffering – whether it is from physical, mental, emotional pain. I learned over the time I spent with Rita that she suffered by carrying a spiritual burden – the fear of being rejected and turned away by her priest who is part of her church community; and the burden of self-blame and not being able to forgive herself. I was filled with so much joy to learn that Rita's spiritual burden had been lifted. It was very touching to hear that Rita was able to find peace within herself again. I was filled with humility to hear Rita say that I had inspired her to find purpose in life again. As I reflect on this conversation, I believe that it was our relationship together that has inspired Rita to find new meaning and courage in her life, and the shared inquiry space that we lived alongside each other.

### Post Script

Rita and I met again in May 2013. We were able to visit and catch up on life events. Every time we meet and every time we part ways, I feel so much respect for her, who she is and the way she gives to others. She was still involved in organizing a fundraiser for orphaned children living with HIV or affected by HIV in Ethiopia. As she told me about this work, I felt so much gratitude and honor for having been a part of Rita's life. During our visit I also shared a copy of her narrative accounts. I took the opportunity to give her an update on my work, my writing about her life narratives and what the next few months would look like for me. After our meeting, I received an email from Rita and it was probably the most touching exchange she and I have had since we met. She thanked me for writing a beautiful account of her life, her experiences and her experiences living with HIV. Both Rita and Ezra read her narratives together and were touched by it. Then Rita, in her email wrote:

> *"Thanks to your [writing] Ezra surprised me with my grandson and his mom, it was [wonderful] to see my grandson and how he grew up. [My daughter] promised I can pick him up every Saturday and spend the day with him. I can take what I get with HIV, one day at a time. [It's] good news about meeting my grandson again."*

Rita's news about reuniting with her son and daughter brought so much happiness to her. But it also brought me happiness. My work with Rita resulted somehow in an unexpected result of healing some of the pain that she experienced in her family. Somehow, the telling, re-telling and writing of Rita's life narratives brought peace and a renewed relationship for her and her daughter.

# Chapter 6: Sifa's Narratives

## Walking Into the Midst of Stories with Sifa

I remember the first time I met Sifa in November 2012. It was a cold Alberta winter day and Sifa asked that I meet her at her home; I agreed. As I drove to her home, my mind was full of questions. What would Sifa be like? What was her life like in Africa? I eventually found Sifa's home and parked my car and walked up to Sifa's front door. She was at the door waiting for me. I noticed a petite, dark woman at the front door. She opened the door for me and said, "Hello." The cold air followed me into her home, but I am soon welcomed by warmth as I closed the door behind me.

We sat on one of the couches in Sifa's living room. I looked around and her home was simple, quiet and calm. I noticed on one wall photos of her children and framed school certificates of achievement for her children. On another wall, I noticed a familiar picture of Jesus. Sifa must be Christian, I remember thinking to myself. That November, we sat together on a couch and we talked for nearly an hour. I remember the questions and thoughts that went through my mind as we met: Will I be prepared to hear stories of Sifa's life? My fear was about hearing stories of violence and trauma. Will Sifa be emotionally okay sharing such stories with me? Will I be alright to hear such stories? After we talked about the formalities of the project and filled out forms, Sifa began to tell me a little about herself and I listened intently to her quiet voice. After nearly an hour, we parted ways and we agreed to meet in early 2013 to continue our interviews.

~ ~ ~

It is February 2013, and the weather is still cold outside. I think to myself that winter is at its peak. It is so cold and snowy outside! I travel to the city where Sifa lives and meet with her for the week. The night before I meet Sifa, I think back to our first meeting in November and I write in my field journal:

*She was a very quiet woman. But I remember feeling nervous when we first met – it was when she told me she is from Rwanda. As soon as she told me where she was from, my initial thoughts were about the Rwandan genocide in 1994. She lived through that time period. Sifa is only 37. We are the same age. We were born the same year, and I imagine she has had a life full of experiences. She has five children: a son, 21; daughter, 16; son, 14; daughter, 9; and daughter, 6. She had her first child at the age of 16 years. I wonder what her life stories were for that time in her life.*

*But I am anxious and nervous – what will I hear when Sifa shares her stories with me this week? I remember reading about the Rwandan genocide and I have seen documentaries about this time in Rwandan history. Some of the things I've learned about this country seem so horrific – how can one survive such a violent time period? I wonder how Sifa was affected by the genocide. How was her family affected? What type of violence did she experience or see? I wonder. I think my anxiety is about hearing very distressing stories of violence. I* *wonder how I will feel or react. But I also worry about how the experience of sharing such stories will be for Sifa. Will I be prepared to provide her the support she might need from me?*

*I did more reading on the history of Rwanda, specifically during the time period of 1994, when mass killings of Rwandans, both Hutu and Tutsi, took place between April and June. I print out a map of Rwanda and its surrounding countries. I thought it might be a helpful tool for Sifa and I as we talk about where she came from. I'm hoping also that by doing so, it can give me some context – the socio-political context that Sifa lived in as a young person. I hope that this will help me follow what Sifa is telling me when she talks to me about her country.*

*I wrote down a few opening questions for our conversation tomorrow. I learned from the first two participants that they had requested a few questions to start off with. With the first two participants, it only took a few opening questions (like, tell me about your family or where you were born) to start off long conversations. So I thought I would do the same for Sifa, just in case it is helpful.*

## Being in a Place of Stories with Sifa

### I remember, I was happy, then I cry.

On the morning of our next conversation together, I drive to Sifa's home. As I drive, I think back to the last time I was at Sifa's home – it was about three months ago. The weather has not let up yet. It is still as cold as it was then, if not, colder. I park near Sifa's home and gather my belongings. As I walk towards Sifa’s home, the cold bitter air surrounds me. I ring Sifa’s door bell and she opens the door immediately for me to come in. I welcome the warmth of her home and her hug. When I enter Sifa’s home, I notice something I didn’t notice before. I see a wheelchair tucked away near Sifa’s kitchen wall and back door. It is big enough for a little child. I wonder who that wheelchair belongs to.

Sifa and I chat for a while, settling ourselves at her dining table. Sifa has not been feeling well with some chronic back pain she has had for about a year. She explains that this pain has worsened over the last six months or so. Medication has not helped her pain. Sifa tells me that physiotherapy has become too expensive for her and she has not been able to follow through with physiotherapy because of this. Our conversation returns to Sifa’s life stories, stories of childhood and life back home in southern Rwanda. Sifa begins to talk about her memories of childhood. I am struck with Sifa’s story of how her happy childhood ended suddenly with the death of her father, marking the beginning of a life filled with hardships, sadness and pain.

**My Family**[10]
Our farm
My Daddy’s farm
We have cow
We have goat
We have chicken
Everything!
Coffee trees
Orange trees
Vegetable plants

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[10] The poems in Sifa’s narrative accounts are composed as found poetry. Found poetry involves taking words directly from the transcripts and arranging them in a poetic and evocative form.

We helped on the farm
My brothers and I helping
My Daddy
Has money
More money
For School
No money
For School
No School

I don't know why?

My job on the farm
Just cooking
Wash dishes
My brothers
My Daddy
They watch all the animals
My sister
My Mommy
Go clean the coffee plants

I dance
I play
I help others
I go to Church
I was very happy.

Sifa tells me, "I was born in Rwanda. I'm now 37 years old. I was born in 1976. My Daddy was nothing – he had nothing. He had no money, no job. We didn't go to school. My Daddy didn't go to school. My brothers and sister and me – we didn't go to school. I come from Butare. It is the second biggest town in Rwanda. Kigali is the biggest, then Butare. But we lived in a farming area. It wasn't easy because we lived on a farm – it was not a town. My father's house is there on the farm. We have a cow, pig, goat and chicken. Yeah . . . my brothers and I were helping on the farm. My brothers, my sister – we no go to school. My father, he no go to school. There was no money. I think it was money. I think my dad just don't want to take us to school because it was more money. I remember . . . It was more money for school. My dad – he has some money because he had cows, some animals. Everything – he had coffee plants, vegetables, orange trees. But he doesn't want to take us to school. I don't know why. We just stayed home to help."

"You and your brothers and sister helped at home?" I ask, hoping that Sifa would tell me more about what that was like for her. Part of me is not surprised that Sifa and her siblings did not go to school. I've read many times before that school fees in most African countries are a major barrier to children going to school. But I am interested in Sifa's story. It sounds like she and her siblings were not forced to work as children to earn money; but rather to work as a member of her family and to help with the chores on her father's farm. I'm reminded of memories of seeing many children in the Philippines, who do not go to school because of the need to work to survive; many of them work in the urban streets of Manila.

"Yes," Sifa continues, "My job, it was just cooking and washing dishes at home. Yes, it was my job to do that. And then my brothers, they were to watch the animals. They help my dad. My sister, she helped my mom to go to the coffee plants. They clean the coffee place. They take the coffee and then, they take it to machine. I didn't go to school. My job was helping. My daddy's family, like uncles, aunties, they live nearby.  My mommy’s family, they lived too far from us.  You have to go two days walking to them.”

“Sifa,” I begin to ask, “What do you remember about your life when you were a child?”  I was so curious to hear more about Sifa’s life as a child. Somehow, her stories remind me of my mother’s stories of when she grew up.  I remember my own mother’s stories of growing up on a farm, how her father (my grandfather) worked on their farms, tending to animals and farms of coffee, coconuts and lanzones fruits.  Though, unlike Sifa, my mother went to school and only helped with household chores when school was done.

Sifa describes, “When I was a child, I remember I was very happy . . . my family we always saw each other.  We were together always.  I liked to go to church with my family.  When I was young, I like to help people – older people. Yes . . . when someone was sick, I like to visit someone when they were sick.  I liked to help.  Still today, I am like that.  I like to help.  When I was young and when I see someone sick, when I see someone doesn’t have food, I go to my house, I take food, I go give it to them.”  Sifa smiles as she tells me about this time in her life.  I immediately see how the memories of childhood brought joy to Sifa then and how the memories seem to bring joy to Sifa now as she speaks about them.  And at that moment I also recognize Sifa’s love of helping others.

Sifa continues, “Yes . . . I remembered that.  Every Sunday we would go to church.  My family, we go to church together.  It was good.  I liked to go to church so much.  Sometimes, I liked to dance too.”  Sifa smiles.  I smile with Sifa and I look at her. I can see that Sifa is fondly remembering memories of childhood. Sifa continues to smile, as if she is thinking back to happy memories. Her simple stories of play and chores on her father's farm begin to bring images to my mind. I imagine a little black girl, going to church with her sister, brothers and parents every Sunday. She is the youngest girl in her family; in my mind I see a happy child, dressed in a lovely simple dress going to church with her family every Sunday; playing freely with her friends on her father's farm; yet showing discipline as a family member and care for her family by doing her household chores. Sifa continues about her childhood, "When I was my daughter, Odette's age, my life was just like playing all the time. Playing outside with my friends. Playing outside with my friends and helping in the house with my jobs. I remember one of my other jobs was to go get water because we don't have the water inside our house. Before we would have to walk like one hour to get water, but then we had water closer to our house. It was good for me, when I'm young."

**Daddy**
I come home from Church
They say
Your Daddy is gone
To jail

I say
Why
They say
I don't know why

I start to cry
And cry
I love my Daddy a lot

And I never saw my Daddy again
He died
I never saw my Daddy again
I was very sad
Every day.

Then Sifa talks more about her father. She mentioned before that her father was put in jail and I ask Sifa about this time in her life. There is a brief silence between Sifa and me. I see that Sifa is collecting her memories and thoughts of this time in her life and suddenly, I feel a sense of sadness in the space around us. I can see sadness in Sifa's face and I can feel her sadness as she recalls a story about losing her father. Sifa describes, "I was in church one day. When I came home, they said, 'Your dad, your dad is gone to jail.' I said, 'Why?' and they said, 'We don't know why.' And then I started to cry and cry because I love my dad a lot. I love my dad a lot . . . I looked like my daddy. We was the same color. He was tall and my color was the same as him. My mommy was very, very, very black. Not my daddy. I was the same color as him. I cry and cry. And I never saw my daddy again."

Sifa pauses and we sit quietly together. I feel very sad as I listen to Sifa's story of her father. It must be utterly shocking and confusing to come home one day, only to learn that one's parent is put in prison for reasons that are not well understood. Sifa looks down, as if in deep thought as she recalls the time she lost her father. "Did you see your daddy after he was captured?" I ask Sifa carefully.

"No, no . . . I didn't see him.  When they took him, he died, I never saw him."  Sifa says quietly.  "I think he was in jail, six months.  Six months.  They never told us he died.  They only tell us because my brother, he went to go see my daddy in jail and they said to him, 'No, your dad pass away.' It was not easy.  *It was not easy* – when your parent passes away, you don't know where he is, and they just tell you he passed away.  We only knew he was in jail . . . we didn't even know he passed away until they said."

I ask Sifa, "Was your daddy in jail because he was Hutu?"  I remember that Sifa mentioned her father was a Hutu man.  I read before that the violence preceding the genocide of 1994 involved the capturing and killing of Tutsi people and Hutu people who were sympathetic to Tutsi people and to a peaceful society.  Although I've read about the Rwandan genocide, I acknowledge that I would never have an intimate understanding of the complexities surrounding the sociopolitical factors that led to the 1994 genocide.  I ask Sifa carefully about her understanding of her father's capture and eventual death in prison.  Sifa's experience of this time in history is a personal one as she was directly affected by it.

Sifa says, "This was before genocide.  There were people, they want to fight – they start to fight.  Before the genocide, there were people who wanted to kill other people like my daddy.  These people, they just say, 'You bad, you bad.' Then they put them in jail like my daddy.  There was fighting everywhere . . . *everywhere*.  They started to take them to jail.  Yes, they take him to jail because my daddy, he’s a Hutu. They was taking some Hutu to jail. Hutu, yes, they took to the jail. They put many people in a small room; people, they can’t move. It was before genocide, there was fighting. My daddy . . . when he’s in jail . . . too many people in small space . . . no food, no nothing. He died there.”

“What was your life like Sifa, after your daddy passed away?” I ask. I can only imagine the pain of a child who loses their parent, especially a parent whom they love so much. Sifa was only a child when her father passed away.

“My life,” Sifa says, “My life, I remember was no happy again. My friends, they came to see me. They would say, ‘Let’s go out to play.’ I would say, ‘No, I’m not happy.’ I was very sad, every day.” As Sifa tells me about her sadness after her dad passed away, I too feel her sadness because a few years ago I almost lost my own father after he suddenly went into cardiac arrest. I remember those moments when I received a phone call and found out he collapsed and was rushed to the hospital. The thought of my own father dying at the time was extremely sad for me. But my father survived and continues to live today. Sifa’s dad passed away when she was only 15 years old. She was just a child at that time. When she said that she was very, very sad – I too feel her sadness. How painful it must be to lose a parent at such a young age – a parent whom Sifa loved very much. I came very near to losing my father as an adult. Sifa must have experienced tremendous loss and sorrow when her father passed away.

“Some of my friends, they got scared of me. They don’t want to come around me because I was very sad. And when they say, ‘Come Sifa, let’s go play.’ I would say, ‘No! You go away because you have a dad. I don’t have a dad.’” Sifa says with emotion. And at that moment, I realize the sadness and grief of a child losing her father. She was really just a child, a child who lost her father under unexplainable circumstances. The hurt and confusion must have been tremendous for Sifa at that time in her life. It was a time that her childhood ended suddenly for she was faced with responsibilities of providing for herself and her mother.

Sifa continues, “I wasn’t happy. That’s why my friends were scared of me. They don’t want to talk to me again because I didn’t want to talk to anybody. After my daddy died, I just stay home, sleep, wake up, sleep . . . I don’t want to eat. When I saw other kids, some girls my age with their daddies, I would cry. Yeah . . . I never forget him, even today. I remember him. I think about him sometimes . . . After my daddy died, I remember my life was not easy. That’s why I try to find a job outside our farm. My mommy was thinking too much – she said, ‘Where’s my husband? Why my husband die?’ There were no answers.”

After Sifa’s father passed away in 1991, Sifa, her mother and siblings continued to live on their family farm. “It was not easy,” Sifa said to me about that time in her life. “I didn’t go to school and I went to town to find a job. We don’t have money. When my daddy pass away, we don’t have a lot. We sell the cows, the pig . . . everything because nobody can help my mommy to take care of the cows. And my mommy, she was pregnant. It was too hard for us. That's why we selled it. My mommy was pregnant when my daddy died. Back home, if you don't have a husband, you have nothing. Because the men help you a lot, farm, animals . . . if you don't have husband, and you have kids, it's not easy. So, I find a job in Butare. I started to work. Every weekend, I go back to see my mom to help her, some money, some food, things like that. I was fifteen, but I would take care of her, very good."

### Bad guy.

Eventually, Sifa, who was only a teenager found a job as a domestic helper for a family in Butare, taking care of a family's children and doing household chores. When Sifa was about 16 years old, she was sexually assaulted by a man who was 35 years old. This assault remains a memory for Sifa, for it brought her first child to her, a son who is now 21 years old.

**Bad Guy**

I was too young
Sixteen
Bad guy
Thirty five
I never know a man
He was first to see me
I was too young
Sixteen

***

I remember I was outside
Raining
Shelter
Pain
The pain
Baby's coming

Women helped me
Then I got my baby there.
My son.
My son.

Sifa recalls, “I was too young. He was bad guy. I was too young . . . In Rwanda, they do nothing for the women if the man is abusing . . . my son’s dad, he abuse me. If it was like here, this Canada, they take him to jail. But in Rwanda, no. They do nothing. *Nothing!* Nothing . . . my son’s dad, he just went back home. I was 16. He was 35. Thirty-five. He was first man to see me, I was too young. I never know a man. Back home you can’t have a boyfriend until when you get married. Yes. No sex until you’re married. If you have sex, you’re not married, you bad girl. People don’t like it if they know. Your family, they don’t like it. That’s why my brother fighting with me every day. He was angry with me.”

“But it was not your fault, Sifa.” I say quietly. I feel as though I have to defend Sifa, in front of her brother, who is not even with us.

“Yeah, but [my brother] he don’t understand,” Sifa says. “Even when I go to hospital after he the man abuse me, nobody asked about him. Nobody said, ‘Why he do that?’ Nobody look for him. That’s why I don’t like my country Rwanda. They do nothing for women.”

Sifa continues the story about her first child and how he was born in an outdoor rain shelter near her family’s farm. She says, “When the baby come, I remember, I was outside. Near our farm. It’s raining. Outside, when it’s raining, they have like houses, some people go there when it's raining. They go there. And then I was walking, just walking and then I felt like the pain . . . the stomach . . . the pain. I just know the baby coming and then I try to go, to go to washroom, but I can't. The raining is come, I feel cold, cold . . . Then I go inside one of the house. Some people, they were there, and then I feel very pain. There was women, men, inside the house. The women, they tell the men, 'Go outside.' They tell the men to go outside. And then they show what I'm going to sit. The women they help me. And then I did my baby there in the house. The women, they help me and then I got my baby. They take me home to my mom and my mom, she was very happy I had baby. Yeah! Because it was very expensive to go to hospital to get baby. And then I was, my mommy, she was not mad to me. That's why she was very happy I get baby easy, no hospital." Sifa smiled at the end of her birthing story. I see that even though she was assaulted at a very young age and gave birth to a baby as a result of this assault, she was still very much a mother to her son.

As I listen to Sifa's story about the birth of her first child, I am in awe. Sifa was just a child, 16 years old, when she had her first baby. Her recollection of the night she gave birth was intriguing. The rain, her pain, her memory of a cold wet night, walking in pain, not knowing exactly if the baby was coming or not. She sought shelter in an outdoor type of shed that covered people when it rained. She was surrounded by people she didn't know – men and women. The wisdom of the women around her helped her deliver her baby that cold, wet night.

It’s an amazing story to me, how she delivered her first baby under these circumstances and how she walked home with a little newborn, with the women who helped her. I am suddenly brought back to my first birthing experience with my first child. The images I have in my mind of Sifa’s first labor and delivery experience are a stark contrast to what I experienced in my first labor and delivery experience. Weeks before the birth of my first child, I remember my partner and I were buzzing around in preparation mode: getting emotionally prepared for the arrival of our child, getting her bassinet ready, her clothes, diapers, car seat, stroller and all the things that we were told to get ready in our birthing class. Sifa’s birthing experience brings perspective to my past birthing experiences. The naturalness of her experience makes me feel like saying, ‘Sifa you are amazing to be able to give birth naturally!’ I think about how we managed to put a lot of buzz into a natural, human experience – the birth of a baby. Even after I tried to deliver my baby naturally, I ended up being surrounded by machines, wires, beeping sounds, doctors, nurses all in a sterile operating room. And even with all this modern technology, my daughter and I managed to go through complications after our birthing experience. It amazes me! I am secretly envious, but not resentful of mothers like Sifa who are able to deliver their babies naturally without any complications. I am so happy to hear that Sifa, at the young age of 16 did not experience any difficulties or complications during the birth of her first baby . . . I bring myself back to our conversation as Sifa as she continues her story.

Sifa says, “Then, my baby about one year, my mommy, her baby came. She was pregnant, eight months when her baby came. I was there when my mommy started to have baby. After baby came, she died. She get baby . . . after, she died. I was there. I was only 17 when my mommy died. The baby died, then my mommy died. Still, my life was not good, after my dad passed away. It was not easy. Then my mommy passed away. It was not easy. After she died, I went back to work. It was very difficult for me to be happy . . . my mind was no good after my mom passed away. I was too young. I have no parents.”

**My life was no good.**

**My Life**
My Daddy
My Daddy was nothing
He was –
No money
No job
We no go to school

My Daddy
Passed away, I-
Fifteen years old
My Mommy
Passed away, I-
Seventeen years old

My Life
Was no good
I was too young
Take care by myself
I was living
By myself.

I sense that after her father's passing, Sifa's life changed forever. When her mother passed away about two years after her father died, that brought more devastation to Sifa's life. Her words, *"It was not easy,"* are soft and simple, but somehow powerful enough for me to feel her despair. The thought of Sifa losing both parents at such a young age saddens me. She was only a young adolescent; she was not yet wise enough to know about the world and the responsibilities of an adult; and she no longer had parents to share the future joys and burdens of life with. It must have been difficult for Sifa. After the death of her mother, Sifa continued to work. But she made a difficult choice for her son. Sifa recalls, "My son stay with me for one year. Then when mommy, my mom pass away, I go to give baby to the grandma. He live with his grandma, the mother of my son's dad. I had to work. I just worked after that. My son, he don't know his father. They said he moved away. They said he did genocide, maybe he killed people. That's why he moved away. They don't know where he is. He is bad. If the government find him, they're going to kill him. I give my baby to his grandma, then I go back to work. My son stay with his grandma until she die."

### Burundi, March 1994.

Diaspora[11] Part 1 – Burundi
You hear
Fighting

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[11] Historically, the term *diaspora* has social meaning connected to the experiences of Jewish peoples' exile from an historic homeland and movement to many lands. In contemporary literature, the term diaspora has been used to describe people's movement from one geographic area to another, often without choice (Agnew, 2005). In the extant chapter, the term *diaspora* is being used to describe Sifa's movement from one geographic place to another, forced often by violence or danger in her surrounding areas, and not being able to return to her home in Rwanda.

Guns
They fighting

Hear the guns
Hear the noise from people

Run away
Night time
Raining
Walking
Running

Just walk
Walk
Walk

You hear fighting again
Close to you
Move again
Just go
One week
Walk
Burundi
I hear fighting.

By 1994, Sifa had been working for the same family for about two years. Both her parents had passed away, she had given birth to her first son who was then residing with his paternal grandmother, and Sifa had met her husband. He was a Congolese man who she met through relatives while working in Butare. We talk more about the year 1994, and Sifa begins by talking about the genocide and her experience of fleeing the violence in her country.

Sifa describes, "It was in 1994, maybe March. . . . it was nighttime. It was dark outside. It was night and rainy time, March. I with my husband and his sisters, his mom. I was asleep already when all of a sudden, I hear fighting at my neighbor's place. I can hear the noise, the screaming. You hear our neighbor, they fighting. It's the same people who took my daddy. They was fighting the same thing like when they took my daddy. You can hear guns, you can hear noise for people, and we start to run away. I got up and I left the house. Yes, very trouble because many people that died. These people, they just run and go to everyone's home. When they came, I went, I just left with the clothes I had on my back. I didn't take anything. I just went. If I don't go they will kill me too. These soldiers, they will kill you. So I just go. I don't know where I was going, I *just go*. Just by foot, just walking, running."

Sifa continues, "It was dark, and I just started running. I don't know where I was going, I just started to run, then walk. Just walk, walk . . . because you don't know where you're going. Just walk, walk. If you see – so many people. We stay like a group, you stay like a group. Then when you hear they start fighting, like close to you, then you move around again. *Just go*. You don't know where you're going. It's like that. You walk at nighttime, morning time. You just keep walking. It's raining, but sometimes it stops. But it's cold at night time. You don't have blanket, you don't have clothes to change in. No food. I walked for days and days until I reached Burundi. It wasn't easy. No food, no water, no shoes. It rained, it was hot, it was cold at night. But we kept walking until we reached Burundi. The UN [United Nations], they go and find people and they come with people to help you. The UN they see our group, little group. They go there to help, they started to help, they start camp. We make camp there with UN. They give us tent, food and water. We were many people at the Burundi camp. We still waiting if the fighting is going down, but we can no go back to our house. We stayed in Burundi for maybe two months. My life in Burundi was not easy because sometime we don't have enough food to eat. You could eat anything you see, you can drink any water you see. If it's bad water, you don't care, you just drink. And then you eat anything you see. It was not easy. We sleep on the ground, there are many people near you. Some people die there for being sick . . . they don't have food. Some children died because no food and no water. No blanket. Nothing. Even it is raining . . . because you're outside, like that. It's hot in the day, at night, it's cold. You sleep like that. It's not easy. *It's not easy.* I don't have good, I don't have a good life there. We have no shoes, just one clothes. There is no bathroom. People just go everywhere – that's why many people die. It was not easy. I would think – *how I'm going to do?* I think too much and then maybe in May, we go to Tanzania."

As Sifa tells me her story that took place in her life in March 1994, I see images in my mind of confusion, chaos among people fleeing their homes because of violence; wandering day and night to find a place away from the violence. Sifa describes living in conditions of extreme poverty in Burundi with other displaced people. There was little or no food, shelter, water and adequate sewage facilities. There were people dying from hunger, dehydration and other disease as a result of these living conditions. As I sit with Sifa, I listen to and watch Sifa tell her stories. She seems flat; she tells her stories with little emotion, soft words, yet powerful enough for me to create images in my head of what it must have been like.

Later in the evening after hearing Sifa's stories of fleeing Butare and living in displacement, I write in my field journal:

*What must it be like to wake up in the middle of the night, in your own bed and own home, to the sound of guns and your neighbors screaming? It must be horrific and frightening. As Sifa told me her story, I can only imagine the panic and urgency that she experienced at that time, waking up to these sounds and fleeing her home in a hurry, with the clothes on her back, not being able to think about where to go. "Just go," she told me, "Just go." These were Sifa's words, simple yet powerful, bringing images of people urgently fleeing the violence. Sifa's stories spoke to the panic and chaos of the night she and her husband fled their home in Rwanda. Sifa's stories of walking for days and days in extreme weather conditions, with no place to go seems unimaginable to me. Her stories of walking with other people who've left their home, reminds me of images from the film* Sometimes in April *(Delume, 2005). This dramatic film portrayed events of the Rwandan genocide, focusing on the experiences of one fictional family. Although this film is fiction, the story that Sifa shared with me today created images in my mind that reminded me of the film: people fleeing, people walking and running from violence, people being found by UN workers, people living in refugee camps, seeing the desperation of people, surviving violent circumstances.*

*When I heard about some of the experiences that Sifa had in the UN camp in Burundi, I didn't feel any more relief for Sifa. Her experiences in the Burundi camp – having no food, clean water, and being surrounded by death, disease and desperate living conditions really shocked me. Perhaps, I had a vision or an assumption that an organization like the UN was supposed to provide basic necessities in life, and yet Sifa's experience sounded like she struggled for some of these necessities while she lived in the Burundi camp. Hearing Sifa's stories earlier really challenged my assumptions about refugee camps – my assumption that camps were safe and somewhat stable temporary housing for displaced people. I went back to one of my books I read years ago about international health issues, including displaced populations living in refugee camps . . . Sifa's stories reminded me that often it takes much time to establish water, sanitation, nutrition, shelter and basic health care – even by large organizations like the UN.*

*I've never met anyone who has lived through such hardship and suffering. I can sense the hopelessness she had at that time. When she looked me in the eye and said, "How I'm going to do?" I can feel the desperation she had at that time. Hearing and knowing her stories of her time in the Burundi camp make me feel a great sense of gratitude for my life today. How fortunate I am, how fortunate my children are to have the basic necessities in life – food, water, shelter, clothing. Every year that the anniversary of my parents' migration to Canada comes, I always give thanks for my parents making the difficult decision to leave their home country to find a stable home where they could better provide for their* *children. I think about where I would be in life right now had my parents not migrated. I still see some of the desperate living circumstances and extreme poverty in the Philippines. I've met many people over the years in the Philippines who were born in poverty and who continue to live in poverty with their children and grandchildren. Living in many parts of the Philippines is about surviving one day at a time; being able to find food for the day; and not being able to plan far into the future. I've met people who have little to no opportunity to reach their potential. It is difficult to find meaningful employment, even if someone has completed post-secondary education . . . Many people do not reach a quality of life that allows people to make choices and gain satisfaction from living. I always give thanks for my parents' brave decision to leave their home country, hoping for better futures for their children. I only wish that all people have the opportunity to reach their potential in life and to bypass the painful challenges of living in dire poverty.*

*I wonder how Sifa sees her new life in Canada . . . does she feel she is far away from the hardships she experienced in Africa? What does her new life mean for her and her children? As I think about these questions, I hope to discover these meanings as I continue my relationship with Sifa.*

### Tanzania, May 1994.

**Diaspora Part 2 – Tanzania**
Sometimes I sleep
Sometimes I'm not sleeping
Thinking-
Where you going to go

Where you going to get food
No food
No water
No clothes.
Boat
Do you know boat?
Two days to get there
Tanzania
Boat
I go to refugee there-
Tanzania.

After a few months of living in Burundi in what sounded like a make-shift refugee camp, supported by the United Nations, Sifa and her husband decided to leave again for a refugee camp in Tanzania. They felt it was too unsafe to return to their home because the genocide continued. They also felt that the experiences they had in Burundi were very difficult.

Sifa recalls, "I didn't think I was going to be okay. No, I didn't. It wasn't easy. I didn't know if I'm going to get better. Sometimes I sleep, sometimes I'm not sleeping because I'm thinking. Where I'm going to go? Where I'm going to get food? After two months in Burundi, I went to Tanzania. I leave with my husband. I think it was May, when we go Tanzania. We stayed there." Then Sifa describes her life events during the time she spent in Tanzania. It's interesting to me that Tanzania, a UN refugee camp had become Sifa's home, after fleeing from the violence in Rwanda. Although it is a place for displaced persons, it becomes a long term place to call home for many people. Sifa and her husband lived in the Tanzanian refugee camp for about two years before giving birth to her second child. Sifa describes, “I get pregnant for my daughter Aisha in Tanzania camp. When my pregnant is like 8 months, we go to Congo to my husband’s family.”

I ask with curiosity, “You went to the Congo?” I knew her husband was from the Congo and I suspect that they likely went to the Congo for family support during the birth of her daughter. It is common in my culture to have family nearby to support a mother and her new born baby during the first month of the baby’s birth. I wonder if this is the same reason why Sifa went to the Congo with her husband.

“Yes,” Sifa continues. “Because my husband family they left from refugee camp in Burundi back to Congo. When I have pregnant for 8 months, I go back to Congo. It’s a long way, but we go by boat. I had my daughter Aisha in 1996 in Congo. Then when I get my baby, after she is 8 months, we go back, Tanzania. I went to Congo because when you get baby, you need help, right? You need some help from the family. My husband family there. I get help like cooking, like massage. When you get baby back home, you’re allowed to have massage for your body, your back. My husband, his mom help me when Aisha born. Then we go back to Tanzania when she’s 8 months old because they started the fighting in Congo too . . . That’s why we move back to Tanzania.”

#### ***Pain.***

Sifa talks a lot about her life in the Tanzanian refugee camp. It was here that she became pregnant with four of her five children. It was here where she experienced serious physical and emotional abuse from her husband. And it was here where she experienced dire living conditions and living just to survive. One morning, we talk about her life in Tanzania and her experiences of surviving and providing for her children.

"My life, Tanzania camp," Sifa describes, "It's better because you get some hospital, you get some housing. That was different from Burundi. I began to feel better there. But when my husband started to be bad to me, I stay the same. I was sad again." Sifa looks down at the table quietly, as if she is collecting memories from her past. Sifa says, "Yes, because he was no good to me. Sometimes, you forget something's happened before, if you have a nice life. But if you don't have a nice life, you still remember. After Aisha was born, he became bad to me. He was drinking a lot. He never drink before. Then, he was drinking a lot. When he drunk, he come to fight with me. I had no clothes, no nothing. When he get money, just drink. And then he comes, he fights with me. I had my son too – my kids they had no clothes. No clothes. Yes. Then, he have bad friends . . . before he was helping me, but when he has bad friends, he start to be bad to me. He abuse me. Sometime he kick me out, I got to find where I'm going to sleep with my kids. He kick us out. Sometimes, I went to sleep like in washroom, someone's washroom with my kids . . . He was no good to me."

Then Sifa shares a very tragic story with me, the loss of her baby while she was about five months pregnant. Sifa says, "I remember, it was 2000. I was pregnant, 5 months. He was going to drink, outside to the bar, I think. Then when he come home, he started to hurt me. Yes . . . I was sleeping with my two kids. Then he fight with me, baby come out."

**Pain**
Your husband
He beat you
A bat.
Whole place shook.
He beat me.
Baby come out
Baby come out
Baby come out
I was bleeding.
Bleeding.

Sifa shares with me the story of how she lost her fourth baby, to the violence she experienced at the hands of her husband. As she describes her story to me, I feel frightened for her and my eyes begin to fill with tears. I try very hard to not let my tears fall. I try very hard. But Sifa's story of the violence she experienced and how her children witnessed this violence overwhelmed me and suddenly two tears slowly fall from my eyes. I pull a tissue from my bag and I quietly pull my emotions back together. The images I see in my mind of Sifa being severely beaten by her husband to the point of her losing her baby are overwhelming. I am reminded of a very personal story my mother shared with me once. When my mother was pregnant with me, she too was kicked violently, not by my father but by a relative. She told me how painful that experience was both physically and emotionally. When my mother told me her story, I felt so much sorrow for her. How can anyone hurt a woman who was pregnant with a child? When Sifa tells me her story, I feel the same sorrow for her as I did for my mother.  Except for Sifa, she lost her child as a result of this violence.  I quietly dry my tears.  Sifa's re-telling of her experience brought tears to my eyes.  Her experience was tragic.  We sit together quietly for a moment and Sifa continues to share her story.

Sifa says, "It was very bad.  I was bleeding a lot.  And then police, they take him to the jail.  He was coming to fight with me in the hospital too."

"He came to the hospital?" I ask, in shock.  Why would a man, guilty of beating a pregnant woman come to the hospital to hurt her even more?

"Yes, he came," Sifa says.  "The security for the hospital they call the police . . . He was very, very drunk.  I stay at the hospital, 1 month."

"One month?"  I ask, knowing that this meant Sifa likely had complications after her violent miscarriage.

"Yes," Sifa continues, "I was bleeding, like 1 month, it no stop . . . They took the baby out.  Then they clean it out the stomach.  They say because it's not clean and nice, I'm still bleeding.  I keep bleeding, 1 month.  I came out, I go home and then after 1 month, I'm still bleeding.  I go back again to hospital and they clean me again.  I stay in hospital, 1 month."

"Where were your children when you were in the hospital?" I ask Sifa.

"They was at my friend's house.  My husband was in jail.  Even if he was not jail, he can't take them.  No!  He's drunk.  How can he take care of the kids?  No.  The government, Tanzania, it's good to help women.  It's not like Rwanda, no.  Tanzania government, they help women.  They take care of kids and women.

But I was worrying about my kids. If they are okay, if they have enough food. They stay with my friend. It was too far from the hospital, it was . . . like 3 hours to drive. It's very far. My kids are 4 and 2 years old. They can't come to see me because the kids, they're not allowed to go to hospital. For 1 month . . . it's not easy. I got better, then I go back home."

***I don't want to but I have to.***

**Surviving**

Those men
You don't want to
But you have to
Because I love my children
I want to help my kids
Let me do that.

After Sifa's hospitalization in 2000, she was able to return to her home in the Tanzanian refugee camp. She tells me that was able to get her children and return to her small house in the camp. It was after her miscarriage that Sifa's life entered another phase in her life: a life as a single mother, trying to find ways to survive and provide for her children. Sifa says, "I still have my small house in the camp . . . a small house, you know, African house. It is wood, small . . . it's no door, no windows . . . just one room. We sleep together, me and my kids. Cooking is outside. Washroom is outside. After I came home from hospital, my life is not easy because I was very sick. It was not easy, but I stayed there with my kids. Like, I don't have money, I don't have money to buy clothes. It was too hard for me." Sifa pauses for a moment, and then continues. "Then my son got sick too. My son, he was on his friend’s bicycle, and then they do accident and my son, he broke his legs. He was like 3 years old. He broke his legs. He was playing. He was on the bicycle and then accident . . . I don’t have money to buy food, juice, sugar, to give porridge to my son. I don’t have money. He was sick long time, like 3 months.”

As I continue to listen to Sifa, I begin to understand that this was a time in Sifa’s life that marked a period of despairing living circumstances. As a result of the utter desperation to survive and provide for her children Sifa contracted the HIV virus. To me, it shows the power of one mother’s love for her children, but sadly, with a terrible consequence. Sifa’s story is incredible and she shares more of her life stories of survival. Sifa says, “My son was sick long time . . . Then I say, *‘How I’m going to do?’* I have no money, my son he’s going to die for nothing! If he’s sick, he can’t eat, only drink. I try giving him porridge, but no sugar. My son, he doesn’t want to eat anything, only porridge with sugar.” Sifa’s eyes widen as she tells me her story and she tells her story with a certain conviction, like a protective mother trying to give what her child needs.

Sifa continues, “And then I tried to.” Sifa pauses for a moment and as a mother, I can sense the desperation Sifa had at that time in her life, trying to protect her children, her son who was sick at the time. Sifa continues, “I met a man, he was from Tanzania. He was bigger than me:

I said, ‘Can you help me?’

And the man said, ‘No.’

And then I said, ‘Can you help me?  Like five dollars?’

And then he say, ‘Where you going to get money to give me money back?’

I said, ‘Maybe I’m going to find a job and give it to me and then I’m going to give it to you, because I want to buy sugar to give my son porridge, because he doesn’t want to eat anything.’ And then he give me the money.

After two days, the man said, ‘Give me my money.’

I said, ‘No, I don’t have money.  Can you wait?  When I get money, I’m going to give it to you.’

Then he said, ‘If you not give it to me, I can sleep with you.’”

Sifa pauses and we sit quietly together.  I feel a powerful emotional response to Sifa’s story.  As a mother, I can understand her need to do anything to provide for her children and to keep them safe.  My heart sinks as she continues with her story and my eyes begin to fill again with tears.  My emotional response to Sifa – sadness, empathy, is overwhelming.  I know how her story will end.  I’ve sat down with women years ago, women who were involved in the sex trade.  I had the opportunity to spend time in one on one conversation with them about how their involvement in the sex trade began.  All of the women I met experienced poverty and abuse.  All became involved in the sex trade in order to survive and/or to provide for their own children.  These women who I met had little choice in how to provide for their children; all made their decisions in order to ensure the safety and health of their children.  Listening to Sifa’s story of her first experience of exchanging sex for money brings memories to my mind, memories of the women I once worked with. As a mother, like Sifa and the other women I knew, I understand their position of needing to provide to their children. But I can only imagine the painful choices that these mothers had to make in order to provide for their children.

Sifa says, “I had no choice. I sleep with him. I don’t like him. It was just like that.” And two tears escape from my eyes, falling again down my cheeks. I look at Sifa as she tells me about this story and I feel much respect for this woman sitting with me. She is a quiet woman who did things for her children that perhaps mothers could not imagine doing – just to provide for her children. The love that Sifa has for her children is clear to me, through her stories told of how she tried to provide for them. Sifa describes having to see the Tanzanian man for about one month to repay the debt she owed him, a debt that was equivalent to five Canadian dollars. Sifa continues, “Those men . . . I don’t want to, but I have to because I love my kids. I want to help my kids . . . I do that. When I was with my husband, I never go around. No! But when I’m alone, I don’t want to, but I have to . . . because I love my kids. I had no choice.”

***For my children.***

**My Children**
For my children
It's no choice
She has one dress
One underwear
He has one pants and shirt
One underwear.

I let them play
Whatever they want
Play all day
It's raining, play
It's muddy, play.

When they sleep
I shower them
I take them to bed
No clothes
I wash clothes
I dry clothes.

Morning
I dress them
Same clothes
Clean clothes
Clean kids
They look nice.

They go
They play
They school
Whatever they want, they play.

When they sleep
I shower them
I take them to bed
No clothes
I wash clothes
I dry clothes.

They say-
I have nothing
No clothing
No food

They say-
See her children

They are always clean
Clean clothes
Clean body!
Even though I have nothing.
I was very happy.

One morning, Sifa and I spend time talking about her children. Through her stories, I learn about the expressions of love that Sifa showed to her children over time and I clearly see how Sifa's feels about her role as a mother. Her first born, a son, was born when Sifa was 16. Though her transition into motherhood was unplanned and in the midst of her own childhood, she chose to take care of her son during his first year of life. When her last parent died at the age of 17, Sifa made the choice to give her son to his paternal grandmother to care for him fulltime. Sifa could not afford to work fulltime and care for her son. So in 1994, she left her son in the care of his grandmother while she worked and supported her son financially. During the genocide, Sifa lost contact with her son and his grandmother. She didn't know of her son and his grandmother's whereabouts for they also fled amidst the violence. For years after that, Sifa believed that her son died. She could not locate them for years. When Sifa arrived in Canada, she began to search for her son again. She contacted old friends; she made contact with anyone who lived near her old farming community in Rwanda. One day Sifa learned her son was still alive.

Sifa says, "I didn't know if he still alive. When I go to Canada, I didn't tell Canada government I have my son because I didn't know if he still alive . . . it was a long time ago since I saw him. I left him when he was almost 2 years old.

I was know, maybe he's pass away already. I didn't know where they go in genocide."

"When did you learn he's alive?" I ask Sifa.

Sifa continues, "When I come here to Canada, I was finding people from back home, people in Toronto and then I asked them if they know Butare, who lives in Butare, if they see my son, is he alive. Yes . . . I ask different people. Then I find out he's still alive, with his grandma. He was fifteen when I know him again by phone . . . I don't know how I'm going to get to him again. It's not easy for me." Sifa found out her son was still alive the year she arrived in Canada. But because she didn't name him on her government documents as her son, she has not been able to find a way to bring her son to Canada to join her and her other children. Her oldest son is currently 21 years old. The grandmother who raised him has since passed away, but Sifa continues to support her oldest son who remains in Rwanda, by sending him to school, paying his tuition and room and board. They keep in touch by telephone. Sifa shows me a picture of her oldest son and I see a dark, slim young man, dressed in slacks, a dress shirt and shiny black dress shoes. "It's my son," Sifa says as she smiles holding the photo of him. Sifa looks proud of her son. She smiles, looking at his photos, but I also see the troubling look Sifa has when she says, "I don't know how I'm going to get him. It's not easy for me. If I had him, maybe he's going to help me too. Help his younger sisters. I don't know when I'm going to find a job . . . maybe he's going to help me too if I had him here with me."

Sifa's next three children, Aisha, Yusuph, and Odette were born when Sifa lived in the Tanzanian refugee camp. Sifa's youngest daughter, Maria was born in Canada. Sifa was pregnant with Maria during her journey from Tanzania to Canada in 2006. Maria was born months after their arrival in Canada.

There's always a certain light in Sifa's eyes when she speaks about each of her children. To me, this light represents of Sifa's love for her children. One afternoon, Sifa shows me a frame that held a photo of each of her children. It was like a simple collage of photos put together with care by a proud mother. Aisha looks like a typical 16 year old girl. Her eyes and her smile are so bright in the photo taken at school; her hair neatly done in braids. Sifa says, "She has a lot of stories she remember, everything. She's only 4 when she see her daddy abusing me. Yes, she was 4. She knows everything. Sometimes she's telling me and I say, 'What? You remember?' She says, 'Yes, I still remember.' And then I was, like, 'You still remember? You was 4, Aisha. How do you know that?' She said, 'I know everything.' She's very smart. She is. She still remember everything. If some I forgot, she know. When she was started tell the story, her brother, like her daddy abusing me, that pregnant, the baby come out. My son, he was very sad." I look at the school photo of her son, Yusuph who also looks like a typical Canadian teenager. He looks serious, but still smiling. There is something about his photo that makes him look like a responsible young man, caring and thoughtful towards his mom and sisters. He plays soccer with a team and enjoys it very much. "Yes," continues Sifa. "My son, he was very sad. He said, 'Maybe baby was a boy.'" I look at the photos of Aisha and Yusuph. They look like very bright children. Sifa tells me they are very nice to each other, like good friends. I am touched by how Sifa describes her children and how they are very kind and loving to each other and to their mother.

Then I look over the photos of her two youngest daughters. Odette is a 9 year old girl who was born in Tanzania. She looks different from her older siblings. Her father was a Rwandan man who Sifa had a relationship with in Tanzania before he himself immigrated as a refugee to Norway. Odette looks like a cheerful and caring child. She has round cheek bones, which sit high as she smiles in the photo. Sifa tells me proudly that Odette is a very kind and quiet child; that she is very caring to her siblings and helpful at home. Then I look over to the photo of Maria. Sifa was pregnant with Maria when she made the journey to Canada from Tanzania. Maria's father was a man who Sifa had a relationship with in the refugee camp. He left Sifa after he learned that Sifa was pregnant. I notice in the photo of Maria a child with a bright smile, she looks like a sweet and playful child, who might be one to always joke around and laugh. I also notice that Maria is small for her size and has unique features in her physical appearance. She is 6, but she looks as though she is a toddler in the photo, she looks as though she has the physical appearance of a person with dwarfism. Sifa says, "My daughter, she's 6 years old, she's no good. She's handicapped. Did you see her wheelchair?"

"Yes, I noticed that before," I say to Sifa. It is the wheelchair I had seen before, tucked away at the back of the house, near Sifa's back door. I had wondered who it belonged to, and now I know. It belongs to Maria, Sifa's youngest child.

"Yes," Sifa continues, "That's for my daughter. Her condition is . . . I forgot the name. I don't know. The short people. She's like that. Her neck and legs, is hurt her. She can't walk too much." Sifa tells me that her daughters' school is about a five minute walk from their home.

I ask, "How does she go to school? In the wheelchair?" And my next thought is about who pushes Maria in her wheelchair. I know that Sifa suffers from severe back pain and I wonder who brings Maria to school in her wheelchair.

"Yes," Sifa says. "She can't walk for that, to school. She can't. Her legs. Hard to. I take her in the wheelchair. Yes, and then she has a lot of appointment. Medical appointment, physiotherapy. I take her in her chair. I don't know how I'm going to work. Nobody going to hire me for, like one week I have appointment, second week appointment. I don't know. It's not easy for me. To find a job. If it's my daughter, she's okay, I'm okay to find a job, but she's not okay. Sometimes she's sick. She has asthma. Yeah. I had many, many appointments. Sometimes I forget. She has a lot of doctors. It's not easy for me. I think, what I'm going to do in the future?"

During our time together, I see the commitment Sifa has for her children, despite her challenging life circumstances. Sifa chooses to take care of her daughter who has special needs, taking her to many medical appointments. One of the most incredible stories that Sifa shares is a story that took place in the Tanzanian refugee camp many years ago. As a mother, it is a story that speaks to a mother's love for her children and her desire to provide for them, no matter what the circumstances or consequences.

Sifa says, "When I separate from my husband, I still remember. Aisha, she have the dress, one dress and one underwear. My . . . Aisha. Yes one dress one underwear. Yusuph, has short pants and shirt. That's it, until one year they go to kindergarten. When they went to sleep, I shower them outside, I take them to the bed, they are no clothes, I wash clothes, I dry, then hang up. Morning, when they have to go to kindergarten, I dress them. The same clothes. They go, they play, until every night I have to wash it. They sleep in no clothes because only one. But when the government have us choose the children, who the parents is good for to wash clothes, for to clean the kids, it was only me first. They chose only me first. Because they see my kids, always they are clean. Clothes, yes and clean body, head. And they say, 'How come they chose Sifa? She has nothing! Many people they have a lot of clothes. Many people have food. Why they choose Sifa?' And then they call me, they're giving me like, presents. It's like everybody like school, party. Like that, they call me, 'Sifa, is the number one to take her kids to be clean.' And then I say, 'Why? It's one clothes?' And then they say, 'It's one clothes, but it's all the time it's clean.' I took care of my kids. Yes. They say 'How you do that?' And then I say, 'No, they play all day. Whatever they want. It's raining, they play outside, but at night, I have to wash it.' That's why every morning, they look nice. I was very happy! Yes! I feel I have nothing, but when I see my kids, it's good. I let them play all day, but I wash their clothes and they are clean every day."

Sifa's story touches me. It's not just a story of how Sifa took care of her children, but a story that shares the meaning of a mother's love for her children. I see the joy in Sifa's eyes as she tells me this story. As a mother, I understand her joy. Even though people criticized Sifa for not having anything, she still took great care of her children, with what they did have. For Sifa, this brought her much joy. It is very clear for me that it was important for her children to be happy and healthy despite the extreme poverty they lived in. Later that evening, I write and reflect in my field journal about my conversations with Sifa:

*When I arrived earlier today, I saw the same wheelchair I noticed the other day, neatly folded up and placed against the back door to their house. When I arrived, Sifa was just resting after bringing her two youngest children to school. Sifa walks her children to school every day and picks them up by walking. She must always push the wheelchair for her youngest daughter who was born with a condition that makes it difficult for her to walk long distances. The school is only a few hundred meters away, but Maria, her youngest must use the wheelchair for she cannot walk the entire distance. I remember thinking about* *how hard it must be to push her child in a wheelchair through all the snow and ice that's outside. It is a government housing complex managed by the City. I just realized that none of the snow has been cleared in their complex – it looks like it never has been cleared. I was always careful walking to her townhouse unit, to not slip and fall on the ice in her complex. Sifa has severe back pain and it must be difficult to push her child in the wheelchair over the thick snow and ice in her complex.*

*Just before I left Sifa's home, she told me again how much she loves her children. I don't doubt it one bit, I told her. When she said "I had no choice" but to find money by sleeping with men in order to support her children, I know that she truly had to choice. Women were not treated as equals to men. That was pretty clear to me when one man suggested that he sleep with her after lending her five dollars to buy food for her children. By their gender alone, I think women are marginalized in some cultures. Sifa spoke to this earlier today. It is completely outrageous and unjust that women who live in poverty are subjected to more humiliation when sex is traded for money in order to survive or provide for their children.*

*Sifa told me a lovely story which really showed how much she cares for and loves her children. When Sifa lived in the Tanzania refugee camp with her children, she told me a story about how she made sure her kids were always dressed and cleaned and respectable for school. She said when they went to school, they would come home, she would let them play and play outside – even if* *it was rainy, muddy or dusty. She let her children be children despite their living conditions. Then at night, because her kids only each owned one set of clothing, Sifa would put her kids to bed with no clothing while she would hand wash their school clothes and underpants by hand, and hang them to dry for the next school day. Sifa did this every night and every morning, she would make sure her children were bathed, fed and had clean clothing to wear for school. Every day, she told me, "Every day." As she told me this story, she would motion her hands to show me how she would hand wash her children's clothing for school. I know her hand gestures – it's the same way my mother showed me how to wash some of my clothes by hand when I was a kid – just like how they do it in the Philippines for those who don't own washing machines. Sifa's story was touching. It wasn't just a story of how she provided for her children and made sure they were happy. It was a story that really spoke to the deep love between a mother and her children. She even said – she only wanted to do her best for them, even with nothing to own and no money to give kids the proper clothing.*

*Spending time with Sifa has reminded me that I have been so fortunate and blessed in my own life. My children are blessed. I have choices in life to make. Sifa did not have any choices in life to make. For so long, she lived to survive, with few choices in life. It must have been so difficult for Sifa when she made the choice to trade sex for money – to provide the basic necessities for her children while they lived in Africa. I am extremely sad that Sifa and her children experienced so much pain, hurt, hardship in their lives. It's an overwhelming* *thought to know that people in this world are faced with such terrible circumstances in life and that people do not have choices to make. Rather they are forced to make difficult decisions just to survive in life . . . I feel so much happiness that Sifa and her children are here in Canada.*

### ***They check my blood, 2003.***

**HIV**
They say-
You want HIV test?
I need it.
They check my blood.
It will take one week.
***
They call me to go there.
I was very scared.
I go to the hospital –
I turn around
I go back home
I was very scared.
***
I say-
I have to go
What I'm going to do
For my Baby
My Baby did nothing
All the mistake is from me
I need to protect my Baby.
From the HIV.

One morning, Sifa tells me about her HIV. Sifa was pregnant with her daughter, Odette and as part of her prenatal care in the refugee camp, she was tested for HIV. Sifa shares her story about this time in her life. Sifa says, "I had my, pregnant for my daughter. She's 9 years now. I had pregnant for 5 months. That's why I get to have HIV test. Yes, clinic tested. It was when you had pregnant in a refugee camp. They have to take you, test if you have HIV. Yes, because they want to protect your child. Maybe August 2003 . . . they was asking me if I want test for HIV. They ask me first. If you don't want it, you don't want it. But, I was need it. Yes, I said test me."

"Did you think you had HIV?" I ask Sifa. When she said she needed to be tested for HIV, I wondered what was going on for Sifa at that time.

"I think yes," Sifa continues, "Because after I separate with my husband, it was . . . I was go for men who I don't know. I think it was three men. Yes. That's why I was think I want to, I want test. To see if I have HIV." As Sifa tells me her story about her experience of getting tested for HIV, I feel a range of emotions from sadness to anger.

Sifa continues to share her experience of HIV testing and diagnosis with me. She says, "Many people, they don't want HIV test. The camp, it has many, many people HIV positive. Many people, because . . . many people, they are like me too, it's another me. Many women with HIV. Some, they had baby, they don't know if it has HIV, they give breast milk for baby. Yes, baby get HIV too. Many, many kids, they die at camp, for HIV. They check my blood. It take one week. When, they not call you, you don't have it. Yes. If you go to do test, if they not call you, you don't have it."

"Did they call you?" I ask Sifa.

"Yes," Sifa says. "They come to my house. They call me to go there to the clinic. And then I went there, but I was very scared. Yes. When I go to the hospital, I turn around again, I go back home. I was very scared. I go back home, I go to sleep. I sleep and then they come to call me again. I say, ‘No, I’m not coming.’ I stay there, home for like two months.”

“Two months?” I ask Sifa. I think that is a long time to carry fear around, inside. Sifa stayed at home for about two months, thinking about her HIV test results. It must have been a difficult experience for Sifa; I sense that Sifa was scared to know the results of her HIV test. She had a feeling it was a positive HIV test because she received a call from the clinic.

“Yes,” says Sifa. “After that, I say, ‘No, I have to go.’ I have to go, I have to know if I have it. They’re going to tell me what I’m going to do for my baby. I changed my mind. I need to know what I going to get for baby. I say, ‘What can I do? My baby there.’ I don’t have a choice, I have it, so I need the help for my baby. I keep thinking about my baby, because my baby did *nothing*. *All the mistake is from me.* I say, ‘I have to protect my baby.’ For one, two months, I was at home, I was very scared. I don’t want to eat, I don’t want to drink, just I was very scared. I keep thinking, I’m going to die. Who going to take care of my kids? What I’m going to do with my pregnant? I was very scared at that because me, I love my children.”

Sifa continues, “It’s not like malaria. If it’s malaria, they give you medicine until malaria gone. But HIV, you have to take medicine for every day, every month. Yes, and then when you get baby, they give you milk you have to give your baby. I was very scared.” As Sifa talks about how different malaria is from HIV in terms of its treatment, I wonder too if she feels there are other things different between the two. We continue to talk about her experience of HIV diagnosis.

"Did you have a feeling that you already had HIV?" I ask Sifa again.

"Yes," Sifa says. "I think, yes, I have it. Because I got headache a long time, headache. I was sick. And then, I sleep with men. I don't like them. I don't know them. But sometime when you sleep with men, you don't like him, but when he say he going to help you, some money, some food, you'll sleep with him. Yes, that's why I don't know where I get HIV. I don't know who gave to me. Because they don't tell you if they're sick. They don't tell you. That's why, when I sleep with them, I told all of them, just sleep, they give me money. I go to buy food for my kids. Sometimes, my kids, they're sick, I don't have the money to take them to clinic. If I see man telling me, 'I can help you,' they can help, they need to sleep with you. Those men. I don't want to, but I have to because I love my kids. I want to help my kids. I think that's why I got my HIV because I sleep with men." My heart aches as I continue to listen to Sifa's story. She describes a time in her life when she felt the only way she could help her children was to exchange sex for money. She says, "I remember when I talk to nurse at clinic:

'You can tell me. I already know.' I said to her. 'Tell me everything. I'm okay with that.'

'You have HIV. Do you know who give it to you?' the nurse said.

'No,' I say. 'I don't know.' Because I know I meet different men, I don't know if they . . . I don't know who have it.

'Are you okay?' the nurse said.

'I'm okay. But I need help for my baby. I don't want to have a baby who has HIV. That's why I need help.' I say.

'Okay, we're going to get help,' the nurse said."

Later that evening, I reflect on my time with Sifa and I write in my field journal:

*I felt such a range of emotions for Sifa as she told me her experience of HIV testing in Tanzania and her experiences while she waited for her test results. I also felt so much empathy for Sifa, as she described how HIV was her mistake, her fault for exchanging sex for money. I can only feel that she did this to survive and provide for her children. I've met many women who were involved in the sex trade and it was remarkable to hear their stories. All of the women I have spoken to in the past became involved in the sex trade to survive or to provide for their children. Sifa described how she felt she had no choice but to have sex with men in exchange for money. This was the only way, she described that she could help her children.*

*I felt incredible empathy for Sifa. I wonder if my reaction was driven by my western upbringing and western society's rejection of gender-based violence towards women or western society's support for gender equality. But when Sifa told me about the lack of choice she had in the matter and how she didn't want to* *do 'that', but felt she had to, it's clear to me that the cultures that shaped both Sifa and me didn't matter: Having sex with men in exchange for money is something that hurts. Sifa described her feelings about these experiences in her life. I felt very sad; I felt anger; I felt a range of emotions . . . These emotions were mine, and I wonder if other people from Sifa's culture would feel the same. I felt sorrow- for Sifa who once lived in such despairing circumstances that she had to exchange sex for money in order to provide for her children; anger- for the men who used the power of their gender to give money in exchange for sex with Sifa; disturbed- that the men whom Sifa approached could not help her out of kindness, but rather out of their gain and disrespect for Sifa as a woman; compassion- for Sifa, a mother like me, who made personal sacrifices in order keep her children healthy and happy; finally, sadness- that the woman I sat with had to experience such pain, humiliation and hardship in her life. I wonder if Sifa was not a woman; if Sifa was not living in poverty; if Sifa had the opportunities for education, literacy, and skill development – would she have experienced the things she did in her life?*

#### ***He's going to kill me.***

After Sifa learned of her HIV diagnosis, she experienced many things in life. Sifa shares many stories about her life during that time with me: stories about fear, stigma, survival, the anticipation of migration, disappointment in life, despair and hopelessness.

Sifa says, “I was sick a lot, tired, when pregnant [with Odette]. Every time, I have headache. Headache, not go away. Every time, I had a fever. Always, headache and fever. I think too much because I was worrying about my baby because I was pregnant. I was worried about baby. But for me, was . . . not really worried. Just my baby, I worry. I was thinking about maybe I’m going to die soon. Who going to take care of my kids? Yes. Every time, if I have my headache, I think I’m going to die now. Because some women in Tanzania, already they have HIV, they can’t live like five years. When I have baby, they give me medicine. Then, no breastfeeding. Then before 24 hours, another medicine.”

I wonder if Sifa informed Odette’s father of her HIV diagnosis. “Did you tell Odette’s father you had HIV?” I ask Sifa.

“No, I didn’t tell him until I come to Canada,” says Sifa. I told him on the phone. I tell him. He said he don’t have it. I don’t know if he have test. Maybe he lying to me, I don’t know.”

“When you were still in Tanzania, you decided not to tell him?” I ask with curiosity. I try to understand the reason why Sifa did not tell Odette’s father of her HIV diagnosis. As a public health nurse, I know the importance of letting partners know of something like this. I acknowledge a tension internally and I realize that Sifa had significant reason to not inform her partner at the time.

Sifa says, “No . . . I don’t want to tell him because I was worrying about that if I tell him, he was no have HIV. I give HIV. He’s going to kill me. Yes.

That's why I was scared that . . . to tell him. That's why I was scared because I don't want to fight anymore. Because he was waiting visa to leave to Europe. I said, 'It's okay. He's going to go, I'm going to tell him after.' And then when I tell him and he say 'I don't have it.' I say, 'That's okay. You're lucky.'" I begin to realize the complexities of disclosing an HIV positive status for Sifa. I begin to understand the real fear Sifa experienced in telling her partner about her HIV diagnosis. It's a fear that is deeply connected to the stigma of HIV, the death sentence associated with HIV, the culturally prescribed gender roles in Africa, and the moral attachments to HIV in her society.

I ask Sifa what made her decide to tell Odette's father that she is HIV positive. Sifa says, "I tell him because I was . . . something in my mind, I say, I want to ask him, maybe he gave it to me. I don't know. That why I want to tell him. I want to know if he has it. If he gave to me HIV. He say, 'No I don't have it.' So, no, I don't know . . . is he liar? Is he liar? That's why, my mind, I don't know who give it to me . . . It's my mistake. It was my mistake because I was . . . if I have like enough money to help my kids, I can't do that. It's *my* mistake." I sit quietly, looking at Sifa as she looks down at the table we are sitting at. How I wish Sifa didn't blame herself for contracting the HIV virus. I take a deep breath in and I let it out slowly as we sit for a moment together quietly. I try to understand the complexity of Sifa's life, around the time of her HIV diagnosis. I see that she experienced a range of emotions during this time: fear, the need to find answers about who transmitted HIV to her; the need to come to terms of having a virus that, in Sifa's society, meant a death sentence. Sifa continues to tell me more about her experiences. She tells me about the last relationship she had in Tanzania before arriving to Canada. It was a man from Burundi, who she met in the camp. This man is her youngest daughter's father. They were in a relationship and Sifa describes that she informed her partner then about her HIV status.

Sifa says, "We met at the camp. He has his house. I went there to his house. I tell him, I had HIV:

I say, 'Can you use condom?'

Then he said, 'Yes, I can use condom.' He said yes. He always use condoms.

Then after time, he say, 'No, I don't want to use condom.' He cut his condom.

He's the one who say, 'No I don't want to use condom.'

Then I say, 'No use condom because I am easy to get pregnant too. If you cut condom it means I get pregnant too.'"

Sifa continues, "I worry about HIV and then I worry I'm going to get pregnant. And then that time, it was true, I get pregnant. Yes I became pregnant and then I tell him I had pregnant, what I going to do? I ask him can he give money, I can go to take the baby out. And then he say, 'No, I don't have the money to give you, to take the baby out.' He said he don't want to give me money to take the baby out, he don't want to give money to go grocery. And he leave like that. He don't want to talk to me anymore. After he knows I'm pregnant, he leave."

At this time, in 2006, Sifa already had her four children, her eldest son, whom she thought died in Rwanda, her second oldest, Aisha who was only 10 years old, her son Yusuph who was 8 years old, and her daughter, Odette who was 3 years old. When Sifa learned that she was pregnant again in 2006, she recalls feeling very worried, angry, depressed and ill.

***I'm going to die in this camp.***

**God Help Me**
Just praying
Crying
God help me!
I'm going to
Die in
This
Camp.

After learning about her HIV diagnosis in 2003, Sifa describes a time in her life that became much more difficult. Sifa says, "When Odette was born she was good. No problems. We went home. It was okay because, it was a little bit okay because they was giving me milk to give to her. It was okay because if you had HIV, that time, they give you milk to give your baby. It's free."

I ask Sifa, "How about your health, for you?"

Sifa says, "It was not good. Headache all the time. Malaria all the time. No medicine for malaria. I only have 35 kilos before. Yes 35. I was very, very skinny. I can't move. No talk. I feel like I had . . . I feel nothing. And there's no doctor to see or to help you in the camp.  It was not enough medicine there. Sometime you have to pay money if you very sick.  How, where I going to get money to pay?  Nowhere.  You're still dead.  The kids, they was eating the food at the camp, they give it to us.  We lived there.  Yes, it stayed the same but . . . not enough.  Just wait like that.  I am sick, I am thinking too much.  Too much stress."

As Sifa tells me more about her health after learning about her HIV, I ask if there was anyone in the camp to help her take care of her HIV.  Sifa says, "No, they can't do that because I'm not taking medicine.  They don't know my CD count.  They don't check my blood.  No HIV medicine for me."  I try to make sense of Sifa's circumstances in terms of having access to HIV medications while living in Tanzania.  I believed that medications were available to people living with HIV in parts of Africa.  I've been under the assumption that living in a UN refugee camp meant access to important medications.  Sifa's story of access to HIV medications is compelling.  She tells me that although HIV medications were available to her, she chose not to access HIV medications.  Sifa describes, "They can give you medicine.  But even if you want, they want to give you medicine, you have to go public place to talk about your life to everybody.  So, before they give you medicine, they will ask you lots of things.  Yes, to talk to you about your life for, to everybody, outside . . . then there is medicine.  But I don't like.  No, because when you go to talk about your life outside, for many, many people, there

. . . like going to a supermarket, take a microphone to supermarket and say, 'I have the HIV.'"

I feel stunned by this. If HIV medications were made available, free of charge, they certainly weren't freely accessible if they asked people to talk publicly about their HIV illness in a public place and how they contracted the virus. "Is it true, Sifa," I ask in disbelief, "That people make you do this before you can get medicine?" There is something unjust about this; providing free, HIV medication to people on the condition of disclosing one's HIV positive status publicly. I ask Sifa if this is true and she affirms this again. I am in disbelief that this how HIV medication was accessed in the community Sifa once lived in. I wonder more about this. I wonder if Sifa's description is something she saw from other people's experience, or if it is what she perceived to be the experience of people accessing HIV medication in Tanzania. I feel one thing is clear; that Sifa's narrative account of accessing medications in her community meant feeling a lack of privacy to one's life, as well as being labeled negatively as a person living with HIV.

Sifa continues, "*Yes*. That's how they do it. Yes, many people, you have to tell that you have HIV. It's not private. If it is your private, you can't get medicine. Before you can get medicine, you have to tell . . . everybody that you have HIV. That's why doctor is going to give you medicine, if you tell everybody. That's why I don't get medicine. It was too hard for me because if I say I had HIV, everybody would have run away from me. It's going to be bad for my children. If my children to school, too, they're going to say 'No, you can stay by yourself. Your mom has HIV.' They do that there. That's why I don't want, why I say no to medication." I learn that Sifa lived with HIV, with no medical treatment from 2003 to 2006, until she arrived in Canada with her children; that three year time period was very difficult for Sifa. She says, "I was sick a lot. I was very, very skinny. Yes, because no food, not enough food to eat. I think too much, I get headache, I get migraine. I was very sick. I was worrying about that, I said, 'Maybe I'm going to die.' It was not easy. I hope maybe God going to help me in the future. I don't want to make my children . . . endure . . . I don't want to put my children to be bad for everybody." Sifa pauses, as if she is finding her words, then continues, "There are many people die back home because no medicine. Many children die because when you have pregnant, you have HIV, you had a baby . . . maybe it's going to have HIV too because they don't have enough milk to give it. You have to give the . . . the mother's milk. And it's not good because the mother's milk has, can have the HIV."

I learn from Sifa that when her daughter, Odette was born in late 2003, she breastfed her for 5 months, because she didn't have the money to buy milk for her. Then she was able to access formula for her baby. Sifa says, "I breastfeed her 5 months because I don't have the money to buy milk for her. I breast her 5 months, and then after 5 months I stop. I was worrying about HIV, then I stop and then I give her porridge and milk. And then she was okay." Presently, Sifa's younger children have tested negative for HIV.

### *God, you can take me. I'm tired.*

Overtime, I learn that Sifa's life in the Tanzanian refugee camp increasingly became filled with hopelessness, despair and hardship. The trajectory of her life was impacted by the diagnosis of HIV, and experiences of extreme poverty and gender power imbalances. Together, these factors created desperate living circumstances for Sifa. I learn that she did many things out of love for her children. But this brought much stress and worry for Sifa over the years she spent in Tanzania.

Sifa says, "My house was broken in refugee camp. When it's raining, rain come inside. And then we have church – church has the house and then the pastor tell me to move to go to church with my kids. I had to stay in church because my house is broken. I stay in church until when I come here. Me and my three kids we stay there. My job at church was just cleaning. Every day I had visitors at church. I cook for visitors. It's my job until when I come to Canada."

Sifa pauses for a moment then continues, "But, it was not easy. My life was not easy. I say, 'God, I think you can take me. I'm so tired.' Then, the UN, they come to meet me, like to ask me questions, 'How's your life going?' – like that. And then they come to us, everywhere. If your questions, if your answer is like, you need help, they find what country want to take you. In 2003 . . . I think 2003, they say I'm going to go to America [United States of America]. The UN, they tell me, 'You're going to go to America.' Then they do everything, visa to go to America. And then after, the UN tell me, 'No, you can't go America because you have HIV. The US, they don't want you because . . . you have HIV.' Yes. And then I say, 'Wow . . . I don't have help because of HIV.' I don't know what they're going to do. I don't know how my children do and then I talk to UN. I say, 'Can you take my children to America . . . I can stay, you can take my children.' And the UN say, 'No. No, your children are still young. You can stay in camp. Maybe we're going to find another country for you.'"

As I listen to Sifa's story of being rejected by the United States of America (US) government because of her HIV illness, I am not surprised because I am aware of the US's past immigration policy of admitting people living with HIV into their country. It was only in 2010 that the US government removed HIV infection from the list of diseases that kept non-US citizens from entering their country (Centers for Disease Control and Prevention, 2011). But I sense the desperation of Sifa at that time in her life – of wanting to let her children have a good life, even if it meant separating from them.

Sifa continues, "My life was not easy. I was worrying so much. I am just praying, crying – *'God help me! I don't want to stay here. Maybe I'm going to die in this camp.* Who are going to take care of my kids? I stayed in my house 1 month. I'm not go outside. I don't want to eat. I don't want to see anyone. I don't want to see inside church. I don't want to see anyone to come to me. That time, I was angry for just God. I say, 'God's no helping me. I don't want to die in this refugee [camp]. I don't want to die here. I don't want to have my baby here, this refugee camp.' I say to God-

‘God, I had mistake . . . This is *my* mistake. But you have to help me because this child, my children, you give them to me. If you give them to me, you help me, so I can take care of them!’”

As Sifa tells me about her experience of having her refugee application being rejected by the US government based on her HIV positive status, I feel sadness for Sifa at that time in her life and for many people who were refused entry into the US because of immigration policy. Later that evening, I write in my field journal:

*How awful for Sifa to be denied entry into the United States based on her HIV positive status. She is the first person I’ve met to have experienced this, though I’ve heard of many people being denied entry to the US from those I’ve met over the years. I remember that this policy was only recently rescinded in 2010; only about three years ago. It must have been difficult for Sifa to receive news that her family was denied entry into the US based on her HIV status. I sensed her desperation at that time; Sifa was willing to part ways with her children just so they could have a better life in the US. I could also sense the disappointment that Sifa experienced at this time in her life. She was at a point in her life where every day living was difficult. It was so difficult that at one point Sifa thought she was going to eventually die in the refugee camp . . . When she told me about her conversation with God, how she was angry at God, I felt so much sympathy for her. Sifa must have felt that she was completely spent. She even pleaded with God, asking why her children were suffering for her HIV. It’s* *like the pain and despair that Sifa experienced at this time in her life had reached its peak.*

### Welcome to Canada.

**Diaspora Part 3 – Canada**
It was fast
They tell you
You can go.
One week
To get ready
Children get ready
Get ready
Do your hair
Take picture for
Visa.
Welcome to Canada.

Sifa tells me that in 2005, a few years after having her refugee application rejected by the US government, she received news from the UN that Canada would accept her and her children as government assisted refugees. Sifa says, "The UN, they help me find other country and then they say, 'You're going to go Canada.' It was 2005. But I couldn't believe it." Sifa looks at me as she describes her disbelief that Canada was going to accept her and her children into their country; that she was finally leaving the refugee camp with her children.

Sifa continues, "Yes, they help me find other country. Then they going to go immigration for Canada, they take me, we do interview, everything. We do checkup. Then after this Canada immigration, they tell me-

'Welcome to Canada,' they say.

'What?' I say.

‘Welcome to Canada, you’re going to go Canada,’ they say.

They say that I wait visa. When my visa come, I’m going to go. I just waited. But I couldn’t believe it!” Sifa laughs. “I just wait. But I didn’t know if I’m going to go because what happen with America. Some people in camp, they say, ‘How come Sifa, she’s going to go Canada? How come Sifa go? She has HIV. How she’s going to work?’ People start to say that. Then I didn’t feel happy. I was pregnant with Maria too and I was thinking about maybe when they find out I’m pregnant they’re going to send me back to camp.”

Sifa continues, “They don’t know if I’m pregnant. Yes, it was just my secret and then my friend’s, that’s all. But my friend, she was who talk to me, good news. She say, ‘Sifa, you’re going to go Canada, don’t worry. You’re going to take your kids to Canada.’ And then when I 2 months, pregnant with Maria, they come to my house. The security guy from camp.

They say, ‘Come to the office. They need you.’

I said, ‘Why they needing me?’

He say, ‘No, come to the office. They need you.’

I remember, I can’t walk. Because a long time, I don’t eat. My leg was like that. Not strong. And then I call my friend. It was my neighbor because when she saw I’m not good, she help me to office. She was sick too. TB [tuberculosis]. She help me to office. And then I went there:

They tell me, ‘You’re going to go this month to Canada.

I say, ‘What? No. You lie.’

They said, ‘You see? Your visa is out. You’re going to go with your kids.’

I say, ‘Wow!’”

Sifa laughs quietly as she tells me the story about when she learned she was going to Canada. By then, Sifa would have lived over 10 years in the Tanzania refugee camp. I think about Sifa’s experience of waiting for days, months and years, wondering when she would leave the difficult living conditions of the camp; I wonder how this affects someone’s sense of hope after living for years in difficult circumstances.

Sifa continues, “But they don’t know I’m pregnant . . . I say, wow. But I still not happy. People in the camp, they say, ‘Why you no happy Sifa? Before you were happy, why no happy? Sifa, you going. Why you not happy?’ I say, ‘About what? I going to be happy, maybe soon. Not today.’”

I try to understand Sifa’s feelings at the time she learned she was going to Canada. She seemed happy with the news of migrating to Canada, yet she didn’t feel completely happy. I wonder if Sifa felt this way because of her experience of being rejected by the US government. I ask Sifa, “At first when you found out you had your visa to come to Canada, you didn’t feel happy?”

Sifa says, “No I didn’t feel happy. I was thinking about maybe when they find out that I’m pregnant, they’re going to send me back to camp. My friends from the church, they make party for me. Yeah, because I was singing in the church, who cleaning church. And then they say, ‘We have to make pie for you.’

I say, ‘Oh, they make pie but I’m not happy.’ They don’t know why I'm not happy. Nobody know I’m pregnant. Only me and my friend.” I begin to understand how Sifa felt at the time of finding out she was moving to Canada. She feared that she would be rejected by the Canadian government because she was pregnant.

It was May 2006 when Sifa and her children received their visas to enter Canada as government assisted refugees. Sifa describes that the month of May 2006 was full of changes, fast changes for her and her children. Sifa says, “May, 2006. May is when I got visa to Canada. We leave camp May 30, go to Canada. It was fast. They tell you, before one week, you can go. To get ready. You have to go. They tell you before, one week you do shopping. To get ready, the children ready. Yes. You get ready to do your hair.” Sifa smiles as she recalls the moments of that month, the days of preparing to leave Tanzania to go to Canada.

Sifa recalls, “Then we go to the airplane place in Tanzania. You have to go to hospital there first, to see if you’re okay to go to airplane, if you don’t have TB [tuberculosis], if you don’t have pregnant, like that. Someone, maybe you can give to some people in the airplane - TB, and then they test you too, if you had pregnant. The people come [from] Nairobi. I was there crying, crying. I said maybe I’m not going to leave, because I have pregnant, 2 months. I said maybe I’m not going to leave. I was thinking that and then they’re calling me to say I can't leave. Then the lady from Nairobi, she was doing checkup, everything. They do the testing . . . And then they tested me, they say I'm pregnant –

And then I say, 'Can I still go to Canada?'

They say, 'You can go because you're still small. If pregnant is 5, 6 months you can't, but 2 months it's too small. You can go.'"

Sifa smiles as she shares this experience with me. It seemed that as soon as immigration confirmed she could still migrate to Canada, that her fears of remaining in the refugee camp were lifted. Even with Sifa's HIV positive status, she learned she could still go to Canada. She describes how the Nairobi nurse explained what to do when she arrived in Canada. Sifa says, "The Nairobi nurse she say gave me paper and say, 'When you go to Canada, like reception, you're going to see nurse. You're going to give this paper to show her you have HIV. Don't show to anyone, just nurse.' And then I took that paper, I say, 'Thank you.' And then we go to airplane. We were in the air and they said, 'You're going to go Edmonton.' They choose Alberta. Many people, they were like for Winnipeg, Calgary, different places. And then they say, 'You're going to Edmonton.'" Sifa describes how she didn't know she was going to Edmonton until they were already in the air en route to Canada. Sifa describes a very long journey from Tanzania to Canada. Sifa and her children travelled from Tanzania to Nairobi to Toronto, and then Edmonton.

Sifa shares memories of her journey with her children to Canada. "We went there for the bus. Three hours on the bus to the airport. There was many. It was like 60 buses. Yes, people going to US, Norway, Australia, it was different, but we meet together. Yes, it was a big place we go to make it together, to wait, to go to bus. It was only me, going to Edmonton. Everyone was going, like, Halifax, Ontario, Winnipeg. Then, we go to airplane, to Nairobi. We go to Nairobi. We stay in Nairobi like a few hours. We go to hotel to eat. Yes and it was a very nice hotel. I don't want to eat. I was sick and pregnant. I think too much because when we were first time place, you don't know where you are. Yeah, you don't have your friend, you don't have nobody to talk to. You don't know English. Just you and your children. We stay a few hours in Nairobi and then we come to Canada. We stopped in . . . I think it's Toronto. Yes, that's when I come here, Edmonton. I didn't choose Edmonton. They chose it, where you go."

As I listen to Sifa's story of coming to Canada, I think of Sifa's courage; about how brave she was to endure years of pain, physical illness, sexual abuse, poverty, supporting her children the best way she could have, and then to leave Tanzania to come to a foreign country. Later that evening, I write about and reflect on my conversation with Sifa:

*Although Sifa eventually felt happy about leaving Tanzania, the journey to Canada was still an overwhelming one. Sifa had never been on an airplane or outside the continent of Africa, to see people who were of different cultures, languages and ethnicities. It must have been an incredible experience for Sifa. I think back to the stories my parents told me about their journey to Canada over* *forty years ago. They were both in their mid-20s, leaving their country for the first time ever. Unlike Sifa, my parents knew the English language because it is the second official language of the Philippines, alongside Tagalog. I think that was one hurdle my parents passed a little more easily. Sifa told me she knew nothing about the English language when she left the refugee camp with her children. It was big challenge for Sifa to overcome. My parents arrived at different times in Calgary, Alberta because my mother was pregnant with my sister that year. She decided to have her baby in the Philippines and then travelled to Canada with my sister shortly after my dad left the Philippines. I remember the stories my dad told me over the years about his journey to Canada. His excitement; the anticipation of starting a new life; the fear of coming to a foreign land, not knowing anyone; the anxiety of finding work, housing; and finding his way through Canadian society all on his own. I remember stories of settlement and culture shock my parents shared with us. I wonder what Sifa's settlement experience was like when she arrived in Canada.*

#### Settling in Canada.

As Sifa continues to recall her journey to Canada, she says, "When they say yes, I was happy to come to Canada with my kids." Sifa says about her migration to Canada. "I was thinking about my kids. They're going to get school. We're going to have a nice life. Maybe no more to say, 'When they're going to get clothes? When I'm going to get food for my kids?' Yes. I was very happy about that. I was happy to say my kids, 'You're going to go to school.'"

Sifa continues to tell me about the time she arrived at the Edmonton International Airport. When Sifa and her children arrived in Canada, it was the end of May, 2006. She was about two months pregnant with her youngest daughter, and her children who were 10, 8, and 3 years old at the time. She says, "Somebody meet me there because I had bag. It had my name on it. And in the bag, it has my file. It's inside, because when we go to airport they give us that bag, they say, 'Don't lose your bag because someone is going to come to see you to airport. If you don't have this bag, nobody going to know if you're Sifa. My papers inside the bag. We arrive and a man just showed me to go to in taxi. I don't know where I'm going. I just go."

As Sifa tells me about this day, I suddenly remember Sifa telling me her stories about fleeing Rwanda in 1994; about twelve years before her arrival to Canada. *"Just go."* She said to me one time as she described fleeing, not knowing where to go. When Sifa tells me that she *"Just go"* when she arrived in Canada, I am reminded of her stories in Rwanda. Only this time, she describes a time of when she *"Just go"* but this time not urgently fleeing violence or massacre, but going towards a new future in Edmonton, Canada.

Sifa continues, "We went to taxi, I don't know where I'm going. The driver maybe knows because we went to reception. It was reception, many people they come, they go there to waiting if you're going to find a house. Taxi drive to reception house. When I went there, they showed me my room. We stayed there like, two weeks. And then they gave us food, clothing. Some people, they come to us. A nurse . . . many people, I don't remember now. They're helping me to find a school. They help me to find anything, even a bank, hospital. They're helping me. They help me see a doctor right away for malaria and HIV. And then after that they helping me to find a house, apartment." Sifa describes how a Swahili-speaking settlement worker helped Sifa find her way in Canadian society, supporting her early settlement months in Edmonton. She was even present for the birth of Maria.

Sifa says, "Yes. They help me to get to apartment for two bedrooms. I stay there like three months, I think. Three months or six months, like that. And then I say, I need like three bedroom because my country, if you have boy and girl, they can't sleep together same room. They need separate rooms, yes. That's why I took it to my translator, I say, 'Can you help me to find a three bedroom, because I don't want my son and daughter to sleep together same room.' And then she help me to go find three bedroom. It was cheaper, too."

I feel relief that Sifa was able to receive settlement support when she arrived in Edmonton about seven years ago. I remember more stories my parents told me about their early years in Canada. They said it was difficult. They knew no one; there were no organizations or people to help them navigate through Canadian society, the health care system, the school system, building skills and employment experience in Canada. I recall my parents saying how difficult it was starting "from the beginning" they would say. They had to navigate their way on their own through Canadian society. I can only imagine the experience of moving to a foreign country, a new culture with a new language and finding my way through a new world. “I’m so glad Sifa. Somebody helped you when you arrived.” I say, “They helped you find school for your kids, told you where the hospital and doctors are, they helped you find your apartment. That is so good you had that support. What else did they help you with?”

Sifa says, “Everything. She was taking me to the hospital, she was my translator. Yes. She take me, even when I go to get Maria, she was with me. She’s very nice. She’s from Congo. But I don’t know where she now. Maybe she’s working other job. She take me to the HIV doctor. I think it was after one week I arrive. I was in hospital. Because I was very sick. They gave me room, the medicine, and then doctor come to see me, and then they already told me, this is your doctor, who’s going to see you about HIV and the malaria too. Yes. And then when I come home, I was feel better, and then my doctor give me appointment to go to see him, me and my kids. We went there and then he continue to give me medicine for . . . because when you had pregnant, it’s different medicine, they give you different . . . they gave me different medicine that I took, medicine every day.”

“Sifa,” I begin to ask, “This is the first time you started your HIV medicine?” I do a quick calculation in my head and I calculate that by the time Sifa arrived in Canada, she would have lived with HIV for about three years, without any medication.

Sifa says, “Yes, it was my first time. And it was okay. It was first time. They say my blood is not normal. Because it was long time I didn’t take medicine. The doctor told me, ‘You have to take medicine every day.’ He give it to me, alarm, for 9 o’clock pm. Every day. I bring my alarm to take medicine.”

In 2007, when Sifa’s youngest daughter was about 6 months old, Sifa and her children moved to her second apartment in Canada. She also began a program where she could learn the English language. It was also in 2007 when Sifa met and began a relationship with a Congolese man in Edmonton. I learn from Sifa that the man she was involved with became abusive towards her over time. Sifa recalls, “This man, no, he didn’t help. He lived with me. When he fighting with me . . . I was very sad to be fighting with him. I say, how we going to live? He going to go fight with me. We was sharing house. But he doesn’t want to pay. When I say, ‘Pay, pay the bills,’ he doesn’t want. He want just fighting. And then I went, I go to English school. One time at school . . . I feel sad, I don’t want to do what teacher said, I was just crying, *crying* and then teacher said, ‘Why? What’s wrong to you, Sifa?’ And then I tell her my story, from him, what he did. I have big [debt], like $1500 for the power. I say, ‘Where I’m going to get money? He doesn’t want to pay. My name is on it, that’s it.’ It’s my name. I was very sad. I say, ‘What can I do?’ And then teacher said, ‘I’m going to help you.’ Teacher check with the office, to tell them and then the office called the police and then the police come to my school. And they ask me what happened. And then I tell them what happen. And then . . . they say, ‘You have to move, to go to the shelter, separate with the man.' He's no good man. *He's no good man.* He was a bad man, he's divorced already, he abuse his wife before."

I ask Sifa, "He abused his former wife?"

Sifa continues, "He abused . . . yes and then he had HIV. He didn't say to me if he had HIV." I sit in near disbelief. I also feel sad because Sifa, after everything she has been through in her life, was in a relationship with a man who was abusive to her. In addition this man never told Sifa he was living with HIV even though they were in a relationship together. I wonder what could compel a person not share their health history with another person whom they are in an intimate relationship with. I am aware that I begin to feel anger towards this person whom Sifa was involved with but I consciously put my emotion aside. "He had HIV?" I ask Sifa.

Sifa continues, "Yes. And women. He lives with woman, he don't want to tell her, just sleep with any woman. And he's no good for my kids too. I was worry, I say, 'No, I have daughter. Maybe one day, I'm going to be asleep, I go to school, then maybe he going to abuse my daughter too.' So I was scared like that. Then they help me to find a shelter, to take to my kids and then after school I went, they give us taxi to go to the shelter. And then they put him to jail, I don't know like . . . like one week, I think. Then . . . they was looking house, that's why they find the house. This one now I am living. I separated from that man. He's no good. He hitting me. No drink, no drugs. Just, he's not nice. But he's not drunk, he's no smoke. He never told me he have HIV."

Sifa tells me that when she arrived in Canada, she did not know any English, she couldn't speak, read or write English. Sifa also tells me that she just learned to write her own name and her children's name a few years ago. She reminds me that she never went to school. Every time I sit with Sifa to talk about her life, I always wonder where Sifa would be in life, if she had opportunities for early childhood education and further education. I feel a great sense of sadness sitting with Sifa, the two of us of the same age, the two of us mothers; yet we have very different lives and life experiences. When I am with Sifa, I think often about what my life would be like had my parents not migrated to Canada. Would I have finished my education? Would I have gone to university? Would I have a job, a house? I always feel such an incredible amount of gratitude for having been born and raised in Canada. My parents have always stressed the importance of education and how lucky we were to be in a country where we were able to go to school. Every moment I spend with Sifa, I am reminded of the blessings we had growing up and being able to go to school. My parents always said that education is the greatest gift one could have.

Sifa tells me about her first formal education experience. She says, "I go to school in daytime, English program. My kids, they would go to the daycare. I study, one year. Program is one who started to learn English before you go to do the ESL [English as a second language] test. It was one year. But I was missing a lot because Maria, she was like 6 months, and she was very sick. Sometimes I miss school like one month, two month . . . I finish school for one year . . . I finish school, I know nothing.  I don't know how to write, I don't know how to talk English.  I finish my English school, it was one year.  I finish that program, and then I take other program for 2 years.  The ESL program, it was 2 years.  Maybe three.  How to write.  But because I was missing too much . . . Because Maria was sick.  But they understand it's not my fault.  That's why I was continue to go to school.  Until when I finish it, I take the course for childcare, for two months, after I finish school.  It's like a certificate.  I finish for two months in 2012, May."

We pause for a moment as I try to map out Sifa's education experience in my mind.  I say to Sifa, "So you did 1 year of the English program and then 3 years of the ESL program, then you finish your childcare certificate."  I am amazed by Sifa's drive to learn a whole new language and to finish a Canadian certificate in childcare.

Sifa replies, "Yes.  When we come to Canada, I didn't know how to write my name.  *No.*  I didn't know anything.  I didn't know how to read.  I don't know how to read the A, B, C, D.  It was too hard for me, but I try my best.  I can read just a little bit.  You see, I read your message.  I answer.  But I understand.  Yes. I can write my name and my kids' names.  Some words, some I know . . . some is hard to know.  But I'm different than before."  Sifa smiles at me as she tells me her accomplishments in the last few years.  I feel proud of the woman who sits with me.  Sifa never had the opportunity to go to school in her life, and experienced much trauma and hardship.  When she arrived in Canada she did not know any English.  She worked very hard to learn what she could of the English language.  It’s very humbling to see Sifa smile at me proudly to say she can write her name and her children’s names.  It’s a wonderful accomplishment for Sifa.

### Finding work.

One morning, Sifa describes the challenges she has experienced in finding employment since she’s arrived in Canada.  Her first few years in Canada were spent settling the children in school, having her fifth child, going to school to learn the English language and to work towards a childcare provider certificate. Sifa says, “I went to school when my baby, she’s 6 months old.  That’s when I start to go to school.  To English school.  Yes.  Then I go to school.  Childcare. But I haven’t work yet, because when I finished to school, my back was still hurt. I can’t go to find a job or do anything because I don’t have . . . my back hurt.  It’s very hard.  How I’m going to work when my back hurt?  I need to work.  And then my daughter too, 6 years old, she’s no good.  She’s handicapped.  Condition is, I forgot the name.  I don’t know.  The short people, she’s like that.  She can’t walk.  She can’t walk too much.  She go to school in the wheelchair.  She can’t walk for that, to school.  I push her in wheelchair.  And then she has a lot of appointment.  Medical appointment, physiotherapy.  I don’t know how I’m going to work.  Nobody going to hire me for, like one week I have appointment, second week appointment.  I don’t know.  It’s not easy for me to find a job.  If it’s my daughter, she’s okay, I’m okay to find a job, but she’s not okay.  Sometimes she’s sick.  She has asthma.  Yes.  I had many, many appointments.  Sometimes I forget.  She has a lot of doctors.”

I pause for a moment, thinking about the daily challenges Sifa experiences in Canada.  Then I ask Sifa, “Do you think you’ll be well enough to work, even part time, I don’t know, is there part time work somewhere?  Like two days a week?”  In my heart, I feel so grateful that Sifa was able to leave the destitute life in she had in the Tanzanian refugee camp.  But as Sifa tells me about how difficult it has been to find stable employment in the last six years, I can sense her feelings of hopelessness; her anxiety of not being able to work.  I ask Sifa if she explored part time work, hoping to bring a sense of hope for her.

Sifa replies, “Yes, I think so, if I find that.  But, it’s not enough, because now I get money from government.  But it’s not . . . but it’s not enough for me.  Yes, rent, food, clothes for the kids, everything.  That is not enough for me.  I think when maybe I have job, it’s going to be more than I have.  I don’t know.”

I feel at this moment that I need to offer ideas and thoughts on what sounds like a challenge for Sifa and her family.  I wish I can offer something that could help Sifa, after all that she has experienced in life, surely I can offer some ideas to her.  I say, “You know, some kids here in Canada, they take summer jobs.”  And I wonder immediately if I have made an inappropriate suggestion.  I remember when I was growing up, many of my friends were allowed to have summer jobs.  I always envied my friends whose parents allowed them to have summer jobs to earn a little money while on school break.  But, my siblings and I were never allowed to hold any summer jobs while we were studying, even during summer breaks.  My parents wished for us to focus only on school and on the goal of finishing school, then university. They worried that we would lose sight of finishing our formal education if we were attracted to the employment world so early. And so I realize at this moment that I may have made a suggestion that might not align with Sifa's dreams for her children.

Sifa replies, "Yes, I try to have my daughter, try to apply for job. For the summer. When they look for job, there's not too much available, because she's a student." Then Sifa quietly laughs saying "Yes, she have to finish school first." That's why I'm not, I'm not going to push my children to work. Because in my life, I have no school. They have to take school first. That is important. That's important for me. I don't want to push them to work. They are nice, they are good school. They like school." Sifa smiles brightly when she tells me how much her children enjoy going to school and how well they do in school and sports. I understand her position on making school a priority for her children, rather than her older children finding working as summer students. My parents always reminded us about the importance of finishing school and university, in order to have a better future and life than theirs. Sifa continues, "I need them to continue school because I'm too old. They are young. They have to see what they're going to do in the future." And immediately, I understand Sifa's wish for her children to focus on doing well in school.

### Living with HIV in Canada.

Over time, I begin to understand Sifa's experience of living with HIV in Tanzania and her experience of living with HIV in Canada. They are very different experiences. I am intrigued that Sifa's experience of living with HIV was experienced differently in two different countries. In Tanzania, Sifa recalls that she could not access HIV medications. It would bring shame to her and her children. HIV medications were available to people living with HIV where Sifa once lived in Tanzania. Although medications were free and available, one had to publicly talk about how they got their HIV, Sifa once described to me. It seemed that there was very little privacy or confidentiality for people living with HIV in Sifa's last community. She was afraid her partner at the time would kill her if he found out she was infected with the HIV virus. Sifa feared that her children would be rejected by other children and parents at their school. Sifa chose to not access HIV medications in Tanzania for these reasons. Because of this difficult choice, she suffered physically and emotionally. Even the news of coming to Canada could not bring her happiness for she felt at the time that perhaps her HIV or her pregnancy would preclude her from migrating to Canada.

In Canada, Sifa was referred immediately to a doctor who specializes in caring for and treating people living with HIV. By the time Sifa arrived in Canada, she had been living with HIV for about three years, without medication. As Sifa describes, "I was very sick. They gave me room in hospital, the medicine and then the doctor come to see me. They already told me, this is your doctor who's going to see you about HIV and the malaria too. And then when I come home, I was feel better. It was my first time to have medicine . . . it was first time. And it was okay. All my kids they tested for everything. And everything is okay. It's not hard for me to start my HIV medicine. No. Now it is three pills. Every day. Three. I get better. No more fevers. When I forget sometimes, my son told me, 'Mom, 9 o'clock. You have to take your medicine.' He knows . . . Now only headache and back pain now. HIV is good now. I feel okay. Medicine help me for HIV . . . When I'm sick I go to my HIV doctor and he say, 'This is not from HIV.' Yes, HIV is good. I'm not sick because of HIV, but headache, back pain. My aunt says I did too much work, I can't sleep in Tanzania and when my husband beat me . . . that's why my back pain come back."

"It sounds like the kids know, all your kids know you have HIV," I say with curiosity. She mentioned previously that her son will sometimes remind her of her medications. "How do they feel about your HIV?"

Sifa replies, "Yes, they know. They are worrying about that . . . They thinking maybe I'm going to die. Yes. That's why they worry. Like, my daughter knows. When we came to Canada, that's when I tell them, I have HIV. I tell them three years ago. And then they're asking me what HIV mean. And then I give them example, like all the many people die in the camp because HIV and then I said, 'Do you still . . . know my best friend in camp, the lady who pass away? She pass away because HIV. Many people die. They understand now. And then they're asking me, where HIV come from. Now they know everything . . . And I tell them everything. I say, 'It come from, like to sleep with men, you don't know if they have HIV, they didn't tell you . . . they give you HIV. But if you have one man, it's okay. Not going to get HIV. If that man also no HIV."

I begin to think as Sifa tells me her story: her children three years ago would have been just teenagers. I think about what they must have felt and experienced after finding out that their mother has HIV. I ask Sifa, "What did your kids say after you told them about your HIV?"

Sifa replies, "They say, 'Mom, don't worry. God going to help us. We're going to help you."

"They said that?" I ask with surprise. I am surprised at the maturity and depth of Sifa's children and their response to their mother. Their response strikes me, for her older children would have been 14 and 12 at the time. It is an incredibly mature reply to their mother, comforting her and showing empathy towards her. There was no blame or anger from Sifa's children when they learned of their mother's illness.

Sifa continues, "Yes. They said that. They say, 'You're going to be okay. We're going to be okay too. We're going to help you for everything, to take care our younger sisters.' They tell me like that. If some time I'm not happy, my son worry about that because he knows if I'm not happy I'm going to get headache. And then he say, 'Mom, why you not happy? Because of me? Me, I make mistake?' If he make mistake, I say, 'Yes.' Why, because every time we fighting with him to wash socks, to clean his room, because he plays soccer. I don't want him to smell bad. When he comes, he takes his socks out and then they put it on their bed." Sifa laughs and continues, "Yes, yes, I say two times, he don't want to clean and I don't want to talk to him again:

He say, ‘Mom,’ when he come to play to me, he say, ‘Mom.’

And I say, ‘No, I don’t want to talk to you.’

And then his sister say, ‘No. Go see your room.’

When he go to his room, he see his socks, he say, ‘Oh, I’m sorry mom. I’m going to wash it.’”

Sifa laughs again, telling me about her children. I laugh with Sifa and find myself enjoying this conversion, as two women, as two mothers, doing what I enjoying doing with other mothers – listening to stories of their children. To me, it seems like Sifa’s children are very concerned about their mother’s health and wellbeing. They are also very concerned about each other and they seem to take care of each other. I am touched by Sifa’s stories of her children.

Sifa continues about her children, “Every day, I take my medicine . . . I can’t . . . I can’t miss one. When I forget, my son, when my son is not here, like 9 o’clock, he calls me. He say, ‘Mama, did you take your medicine?’ . . . Yes, sometimes I forget, he say, ‘Mama, you have to take your medicine!’” Sifa smiles and laughs as she tells me how her son reminds her from time to time about her medications. Sifa says, “My kids, they are worrying about that. It’s maybe they know I’m going to die. Yes, that’s why they worry.”

We sit quietly together for a moment and many thoughts enter my mind. Sifa’s stories are incredible and powerful. Listening to her stories about her life in Tanzania, to her journey to Canada, to her experiences of settling in Canada, with her four children makes me feel an incredible amount of respect for Sifa.

“You’ve had a long life Sifa.” I catch myself speaking my mind and I realize the awe I have for Sifa. I’ve never met anyone who has lived through and survived the conditions that Sifa has.

Sifa quietly says, “Yes,” and pauses. Sifa continues, “It was okay, I be okay because I’m here now, this Canada.”

I remember Sifa mentioned she has siblings and I wonder about them. “Your brothers and your sister are they still back home in Rwanda?” I ask.

Sifa says, “Yes. I still talk to them.” I wonder if they know about Sifa’s HIV illness.

“Do they know you have HIV?” I ask.

Sifa says, “They don’t know. Just my son in Butare . . . Maybe if they know, they’re worrying about that, because back home, when you have HIV, you’re not going to live like five years. You pass away, because you have not enough money, not enough food. So they don’t know. They live in refugee camp for Burundi and then after fighting, they go back home, Butare.” I understand Sifa’s decision to not tell her siblings of her illness. I remind myself of the complexities of HIV illness in African communities, the beliefs towards HIV illness, what it means for people, how people feel about HIV, and how people perceive HIV as a death sentence. I understand Sifa’s reason for not sharing her illness with her siblings in Rwanda; it was a way for Sifa to not worry her siblings in Rwanda.

Later that evening, I reflect and write in my field journal:

*Sifa is only 37 years old, yet she's had a lifetime of experiences- mostly difficult and challenging life experiences. Every time I step into Sifa's home, it is quiet and peaceful and I wonder how much of a contrast her life now in Canada is to her life in Tanzania. Each time I spend with Sifa in her home, I notice the silence. Usually, Sifa greets me into a quiet home; her children gone to school; the television off; no sounds of music or anything in her home. I have the impression that Sifa lived a very quiet life at home. I believe she left the home often for her medical appointments or for Maria's medical appointments. She seems to live a very quiet and private life. One time I asked Sifa if she had any friends in the community and I remember that she mentioned she has made some friends in her church community. But I wonder if she has a broader network of friends who can support her emotionally in her life, living with HIV, living as a single mother, raising young children. I sense that her main social support comes from within her family: her two teen age children and two younger children. I have the impression that her family is very close; her older children help with house chores and caring for their younger siblings, especially when Sifa is not feeling well. I very much respect the strength of Sifa's family unit and how they seem to count on each other for emotional support. I am reminded again of my own family growing up. My parents led very private lives and they encouraged us to do the same. They allowed us to have some friends at school; but I remember how my parents always taught us the importance of counting on each other in the family, to help each other out as best we can. They often said, "Blood is thicker* *than water," in our mother tongue and I only understood what they meant by this as I grew into my adolescent years. It meant that we had to nurture our relationships with each other within our family; that family is always first; friends, second. I think part of it too, was a way for my parents to try and preserve our familial and cultural values. I wonder if it is the same as Sifa and her family.*

*When I asked Sifa about her life now in Canada, as a person living with HIV, she replied by saying her HIV is ok. I understood that her physical health was fine and that she has responded very well to her HIV medications. She never shared stories about stigma or discrimination in Canada, as a person living with HIV. I wonder if she has ever experienced this in our country. I assume that she hasn't because she didn't share any stories with me related to this. She did share stories with me about stigma and discrimination in Africa; which is why she chose not to access HIV medications in Africa.*

*I am also surprised that Sifa has asked to use her real name in this research study. She doesn't seem to be afraid of using her real name as I write her narrative accounts. To me, this seems like the fear she once had in Africa about people knowing about her HIV illness is no longer with her in Canada. It is something that I need to explore more with Sifa.*

### Thoughts about the future.

It's the end of February 2013 and Sifa and I meet for our fourth time together. We decide together that this would be a good time to take a break and then meet again in the next one or two months to continue our conversations. I noticed the other day that Sifa's fruit bowl was empty. At the beginning of the week, it had bananas, apples and avocados. Today, I bring a bag of fresh fruit for her and her children to have together. Sifa greets me at her door, into her warm home. We sit together again at her dining table, talk about our week, our children, and get settled for our conversation together. After thinking about all that we talked about in our previous meetings, I am curious to know more about Sifa's outlook on life today and in the future. I ask, "Sifa, now that you're here in Canada and you think about your HIV, do you think about your HIV still every day?"

Sifa replies, "Yes." And she pauses for a moment, as if she is collecting her thoughts. "Yes, but not the same thing, like when I still live in Africa. It's different because . . . my kids, first. They are okay. They go to school. They're not going to say, 'What are we going to eat?' Yes, I'm good, like to know with my children, if I am . . . when if I'm die, my children, they're going to be okay, I think. That's why I'm not worrying too much. I am worrying, my life before, because sometime when they need something, I don't have it. That's why I have, I think too much. Now here in Edmonton, how I'm going to get money? How I'm going to work? When I'm going to get job? I never had job." I remember Sifa telling me about how challenging it would be for her to find a job with her daughter's numerous medical appointments and her own appointment with her doctors.

Sifa continues, “I have money from the government. They’re helping me some, but not enough. But I can pay house, I can have some money to buy the food. It’s not enough, like you working. Sometimes if you work, you get enough and then you give money [tax] to government. I can be very happy if I say, ‘I can work,’ because if the government helping me now, it’s almost six years now, the government helping me. *Six years*. I’m not working. I’m not do anything. They’re helping me, money because they take tax from you, because you’re working, for somebody who’s working. I wish I can work, so the government, they’re going to take my tax to help someone else like me. But.”

Sifa pauses and I sense her emotion as she talks about her desire to work like other people. I ask, “You wish you can work?”

Sifa says, “I wish I can work.” Sifa sits quietly for a moment and I see she is thinking about something. She continues, “Because when they take tax to some people, it is to help me. I need to help someone too. Yeah, it’s to help, I’m happy to see Sifa working, that tax, how much tax the government takes from Sifa, to go to help to someone like Sifa. *Yes*.”

“You’d like to do that?” I ask Sifa. I understand what Sifa is trying to say to me. I can understand the thoughts she has in her mind and her desire to work and contribute to Canadian society and to help others like her.

“I’d like to do that.” Sifa says looking down at her hands on the table. She is full of thought; I can see in Sifa’s eyes when she looks back at me that she is thinking about something.

"Do you think there will be a day when you can find work?" I ask Sifa quietly. Sifa begins to cry and I see the emotion this question brings to Sifa. We pause and sit together as Sifa sobs. I reach out my hand to place on hers and offer her a tissue. We sit a while longer together without speaking, giving Sifa the space to find her words as I try and comfort her.

Then Sifa begins to speak again, as her tears continue to fall down her cheeks, "I know the government, Canada, they're just good, they help, the government Canada because . . . nobody going to take care of my family like that, no one. *No one*. I don't know if I going to be like that, no one going to take care of my family like that. I'm so happy to come to Canada. I'm really happy. I wish I can have big life, I can work, I can help someone like another me." And Sifa continues to sob. I give Sifa the space to experience her emotions about being in Canada and thinking about her dreams to work and help others like her. I remember back to a time with Sifa told me she loved to help people when she was a little girl. It's clear to me that Sifa still loves to help other people. But at this time in her life, it's only a dream that she hasn't been able to accomplish yet as she continues to work through some of her life circumstances.

After a moment of time, I look at Sifa who sits quietly looking out her window. I say, "Sifa, you just give it time. And you know you have your kids, who are going to school. One day they will finish school and be able to do what they want to do."

Sifa smiles and she says, “Yes. Even my daughter, she say, ‘Mommy, I wish when I finish school, I finish my university, I’m going to go to Africa to take kids . . . to help kids.’” And again I am taken by Sifa’s children’s insight and maturity; their desire to give to others.

“Your daughter says she wants to do that?” I ask. I am impressed again by this child’s perception and empathy of others.

“Yes.” Sifa replies, “She want to do that because she’s so sad when kids they don’t have the food, they don’t have parents, parents pass away and like the parents that pass away for HIV, for everything, they have nothing. She say, ‘Mom, I wish I can help that.’ And then I said, ‘Good for you. You’re going to help, you have to go to school.’ That’s the most important. I’m not worrying too much because . . . I didn’t know if this Canada, they’re going to help me like that. It’s almost seven years. They’ve been a big help. Yes. I went to school for free. They give me money. They pay me to school, they pay me house, food and everything. Even now, I have not enough money. Before, when I go to school, I have a lot . . . it was big income. When I went to school, they was give me $1700. They started $2000, and then after that, they cut it. They give me $1700. It was okay. But now they give me $1100 every month. It’s not enough. It’s not enough, but I have no choice.”

As Sifa says this, I feel sad that she feels she has no choice. I am sad because she has lived an entire life of not having choices. I wish that Sifa could take advantage of the choices here in Canada. It’s the most wonderful thing we have in this country; the ability to make choices. But I realize too that it can be difficult to make choices if you don’t see where they are or if your choices are restricted by issues such as poverty. I become curious about Sifa’s understanding of her social assistance and employment circumstances. I hope that she is able to access the resources that are available to her in the community. I ask, “Do they say how long they’ll help you with the money?”

“Until when I get a job,” Sifa replies. “Yes. Just the money, they stop when I get job. Yeah, that’s why I’m worrying about that because sometime when I get a job, I start to work and then if I start to sick . . . What will happen . . . because you can’t work 1 month and then you stop because I get sick or Maria get sick. That’s why I’m worried. And then, when I went to apply someone, I still remember, when I went to apply job, when I do interview for talking, I’m okay, but writing and the reading, I’m not okay.” And I remember how Sifa told me very early in our relationship that she did not know how to write or read in English or in Swahili. I don’t want Sifa to lose hope in finding work that will provide her with adequate income and some financial stability for her and her children. I also begin to understand her choice to stay on social assistance for now, as it seems to provide her with the stability of a small income, while being able to attend to the health concerns and appointments of her daughter and herself. I tell Sifa about an organization that provides literacy skills building for newcomers in the city. I give her the phone number for this organization in case she finds this information useful one day.

I ask Sifa if she thinks about the future and she says, "I think about the future. Where I going to be. I don't know . . . Doctors don't know how long I live because he's human, like me. He don't know even if I'm going to live like twenty years, thirty years. But he tell me some people with HIV live long time. He told me that. But I don't know, I can't believe it. I know I'm going to die. When I am sick, I say, it's almost I'm going to die. Maybe doctor say you're going to live like twenty years, and then you live five years. You don't know. He don't know too." Sifa pauses then says, "If God say, come to me, you go. I feel okay. Medicine help me, because when I'm sick, when I'm sick I go to doctor and doctor say, 'This is not from HIV.' I begin to understand Sifa when she says her HIV is 'okay'. Her current health conditions do not seem to be HIV-related, but rather related from years and years of emotional and physical stress.

Sifa says, "My HIV is good. I'm not going to be sick because HIV. When I'm sick it's like, normal, some people sick. Like headache. Like back pain . . . Even this day, this Canada, I can die. I was refugee camp before, I said, 'Who are going to take care of my children? They don't have school, they don't have anything.' It was worrying so much. But now, if I die today, I think it's going to be nice for me, because I know where is my children. They're going to be good. They're here. Because back home, it's not easy for refugee camp. You don't have your auntie, you don't have your grandma, you don't have the grandpa. *Just you*. *No family*. If I pass away there, nobody going to take care of your kids. They're going to go like, outside. But this Canada, they're going to, Canada, they're going to take care of them. Yes. School, food, dress. When I come to Canada I was very sick. Now I'm okay. My kids, okay. They're going to be good if I die today."

Later in the evening, I think about the time I spent with Sifa and all of the conversations we had together, her tears, her sadness, and her thoughts about the future. I write in my field journal:

*It was an emotional morning with Sifa today – both for Sifa and me. We talked about a lot of things including her migration experience, leaving the Tanzanian refugee camp to make her way to Canada with her children; and her early years of settlement in Alberta. Somehow, every time I am with Sifa and listen to her stories of experience both in Africa and in Canada, memories of my parents' migration story and growing up as a first generation Canadian-Filipino come to my mind.*

*When I was growing up, my parents always reminded us about how lucky we were to be in Canada: that we would have better opportunities for school, education and work. Both my parents came from working-middle class families; they were both educated with post-secondary education; my mother came from a mostly-agricultural family, while my father came from a family of teachers and engineers. Yet they still felt the need to leave their home country in search for a 'better life'. I ask myself, what does it mean to have a 'better life'? After hearing Sifa's stories of desperate living conditions in Tanzania, I can understand her need to find a 'better life'. Sifa did not have stable housing, education or a* *peaceful society. She experienced years of physical and emotional stress, abuse and violence. It makes me wonder about what exactly did my parents escape from in search for a better life? They had housing, education and a peaceful society. But as I think about my family's stories and Sifa's stories, I realize that a 'better life' is something that means something different to different people . . . For my parents it was about finding a peaceful, just and equal society where everyone had the equal right to education and employment. For Sifa, it meant finding a society where there was shelter, food, peace and education for her family . . . It's interesting to me, how a 'better life' is defined differently by people . . . It really depends on where a person comes from; the type of life they have lived before migrating to another country.*

*Sifa's stories make me think about my life again and where I would be if my parents did not make the decision to leave their homeland more than 40 years ago. I'm almost certain life would be very different had my parents not migrated to Canada. My Mom and I talk about this every now and then. We would ask ourselves where we'd be in life, if they had not left their homeland. Life would be very different. I still see my relatives who remained in the Philippines. Life is not easy in the Philippines. There are very high unemployment rates; people, even those with post-secondary education have difficulty finding meaningful employment; poverty is rampant in the Philippines, the gap between the rich and poor widening; along with poverty comes a myriad of social issues – lack of stable housing, mental health issues, addictions, homeless children and youth,* *violent crimes and so forth. I find it very interesting that my parents left a country where there was a seemingly a good quality of life. Perhaps they predicted that people's quality of life would decline in the future. I feel completely blessed to live in a society where there are employment opportunities for people, where there is publicly funded education for all children, where there is peace, and where there is opportunity to reach one's potential in life. I am especially thankful that Sifa and her children are now living in Canada, enjoying a better quality of life.*

*When Sifa cried earlier, explaining her dreams of being able to work in Canada, I felt incredible empathy for her. I sensed how difficult it has been for Sifa to not be able to work like other Canadians, contributing to society, and being able to help others like her. At one point in our conversation today, Sifa began to cry. I think she felt overwhelmed at the time – we were talking about her life in the refugee camp up until her life now. We talked about how difficult it has been for her to find work and earn money even though she is here. At one point, she even explained to me that she feels badly. She said people like me are working hard, and that people like me contribute taxes to support people like her. She said one day she hopes she too can work, pay her taxes and help people like 'Sifa', she said. She was so sincere and at that moment when she said that, she started to cry. We sat quietly for a moment and I put my hand on her arm. It's ok, I said to her. It really is. I told her that one day when she is ready and able to work, she can. And her children, when they finish their education will be able to* *work and help others too. I can see from Sifa's stories of her children that they work hard in school, enjoy school and have the desire to help others when they grow up. It is such a blessing for Sifa to have children who love their mother and see the importance of helping each other . . . When we finished our conversation earlier today I gave Sifa a big hug . . . I want so much for Sifa to know that things will be ok. I also told her how happy I was to see that her children are so supportive of her and of each other. We parted ways earlier for the meantime and planned to meet again in a month or two.*

## Closing Reflections

Sifa and I closed our research relationship in late summer of 2013; but we continued to keep in touch after this. As I think about the time I spent with Sifa, I think about all of our conversations together and the very personal stories and life experiences that she shared with me. Sifa, only in her thirties, has lived a life full of hardship and despair. She lived a life of displacement, poverty, and survival. These experiences shaped and played out in Sifa's life and in her experience of living with HIV. I often wonder how different Sifa's life would have been if she was able to go to school; if her parents didn't die when she was so young; if she was employed. I even wonder how gender roles influenced the many tragic experiences she's had in her life.

The most compelling thing I came to understand, after getting to know Sifa, was her experience of living with HIV in Africa and in Canada. Sifa's narratives about stigma, fear, and privacy played out differently in each country.

Also, these experiences impacted Sifa’s physical and emotional health differently in each country. She never shared any stories of stigma or discrimination in Canada, as a person living with HIV; I wonder if it is because she lives a very quiet life at home now; or if she hasn’t experienced stigma. These are the silent and untold stories that I will continue to think about. I remember when Sifa described how she didn’t have the same fears about living with HIV in Canada as she did in Tanzania. Perhaps this is the reason why Sifa was very much willing to share her personal stories with me, so openly. She feels that she and her children will be okay, even as a family who has been affected by HIV. She feels a sense of security in Canada that she did not feel in Tanzania: the she and her children now have a home, food to eat, school, clothing, medication for her HIV and safety from anyone who might hurt her or her children because of her HIV illness. Sifa’s experience of living with HIV in Canada has clearly been shaped by her storied past.

## Chapter 7: Making Meaning of Experience

In this chapter, I look across the narrative accounts of Lesedi, Rita and Sifa to discern resonant threads. It is what Clandinin and Connelly (2000) described as the transition point of moving from interim research texts (narrative accounts) to final research texts. Attending to resonant threads allowed me to look at the narrative accounts from a different vantage point. Experiences of participants and my own were in a metaphorical conversation with theoretical understandings. Developing narrative threads required me to move back and forth between field texts, narrative accounts and my ongoing experiences alongside the participants. One of the greatest difficulties I experienced during this time was to resist deconstructing each one of the narrative accounts for themes. It would have been very practical to pull themes from each narrative account relating to family exclusion, stigma, spiritual health, physical health, gender roles, cultural influences, and so forth. In fact, early in this phase, I began by looking at each narrative account and thinking about emerging themes. It was a path more familiar to me as a qualitative researcher. But as a narrative inquirer, I stopped and reflected upon the experiences of Lesedi, Rita and Sifa and turned again towards narrative inquiry. The challenge of developing research texts in narrative inquiry is that there is no formula or format to follow. Interim research texts, co-composed with each participant needed to be explored further using a narrative inquiry lens. It was only with time that I could imagine final research texts without over specifying and without limiting boundaries (Clandinin & Connelly, 2000).

## Narrative Threads Woven Through Lives

When I re-visited the research puzzle of this study, understanding the experiences of African immigrants living with HIV in Alberta, and reflected on the narrative accounts for Lesedi, Rita and Sifa, there was no doubt that each person's experience of living with HIV in Alberta was unique and complex. The challenge for me was to step back from each individual relationship I had developed and attend to narrative threads that wove through and across Lesedi's, Rita's and Sifa's narrative accounts. I too was aware that as a narrative inquirer, I needed to move from the mere act of telling a story, to engaging in conversation and dialogue with stories, reliving and making meaning with stories (Clandinin, 2013). The following narrative threads resonated: stories to live by, which includes searching for narrative coherence and living in the midst; the notion of found and chosen communities; and narrative interlappings.

### Stories to live by: The roots of a tree.

"He who does not know how to look back at where he came from will never get to his destination." (Rizal, Translated, n.d.)

I remember when I came across this quote many years ago. I was an undergraduate student in university and I was having a discussion with my father about my involvement with the university's Filipino student association. My father told me about José Rizal, an important person in Philippine history, an author, poet, physician and scholar who, in the 1800s, wrote about the European colonization of the Philippines. His written work reflected his experiences and perceptions of European colonization. This quote not only speaks to the importance of people remembering who they are as people, but also to the importance of knowing one's history in order to understand one's identity. It was my relationship with Lesedi, Rita and Sifa that reminded me about José Rizal and the ways in which I understood his work. I thought about the importance of looking backwards, in particular when Lesedi talked about his mother. During my conversations with Lesedi I saw how deeply his life was shaped by his mother, but also by the social and cultural stories that made it difficult for him to maintain a relationship with his mother. I too have come to know how deeply the absence of his relationship with his father has shaped him. His experiences spoke to the importance of one's history in the shaping of one's unfolding identity. The word history in this sense is not limited to knowing one's family, culture, ancestors, and spiritual practices. Rather, history is meant to encompass what Huber, Huber, and Clandinin (2004) call *stories to live by*.

Stories to live by are narrative conceptualizations of identity that are shaped by one's past, present and future; they are shaped by experiences in the relational, temporal, contextual, the personal, and the social (Huber et al., 2004). Narrative forms of identity include narratives of experience from past and present, and those that have not yet happened. How stories develop and shift over time and how these stories shape and are shaped by multiple, interconnected contexts of where people live contribute to understanding one's identity (Connelly & Clandinin, 1990). Narrative forms of experiences and identity continue to shape and unfold temporally and in place (Crites, 1971).

The narrative quality of experience can be related to the types of stories told by people. Stories told, seen, or heard directly by others are those that Crites (1971) calls mundane stories; stories that are articulated descriptively and chronologically. However, it is sacred stories that give meaning to mundane stories; these are the stories within a story, the stories that shape and give narrative quality to experience (Crites, 1971). As Crites (1971) described:

> Set within a world of consciousness, the mundane stories are also among the most important means by which people articulate and clarify their sense of that world. In order to initiate their children in 'the ways of the world,' parents tell them stories—although in recent times, particularly, the problem has arisen that the children find themselves having to make their way in quite a different world, for which they have to devise quite different kinds of stories than those their parents taught them. Sacred stories, too, are subject to change, but not by conscious reflection. People do not sit . . . and think themselves up a sacred story. They awaken to a sacred story, and their most significant mundane stories are told in the effort, never fully successful, to articulate it. (p. 296)

Further, "the narrative quality of experience has three dimensions, the sacred story, the mundane stories, and the temporal form of experience itself . . . [these]

three narrative tracks constantly reflect and affect the course of the others" (Crites, 1971, p. 305). That is, the dimensions of experience (Crites, 1971) are always in conjunction and never separated. It is the sacred stories that people awaken to, that come to people's consciousness and form part of people's ever changing identity. In this sense, these are what Huber and colleagues (2004) term stories to live by. That is, stories told are "personal, reflecting a person's history, and social, reflecting contexts in which people lived" (Huber et al., 2004, p. 181). When I look at Lesedi's, Rita's and Sifa's narratives, I see that each of their stories to live by, their narrative forms of identity, are unique. Each participant composed life narratives in a way that uncovered stories from past (childhood), present (adulthood) and imagined future. As well, each participant's narratives were rooted in place: places of birth, childhood, 'growing up', places of migration, and eventually places in Canada.

Although the research puzzle for this study focused on the experience of HIV, the experiences of living with HIV were not told as a singular story. Rather, stories of living with HIV were intricately woven with life stories, never separated. This study and its findings were unique. Like many studies conducted in Canada, present-time social factors were explored in the experience of living with HIV. However in this study, familial, cultural and social narratives were also composed by each participant in the search for narrative coherence. Each participant and I began to see the intricate weave of narratives from past and present, and how this shaped each participant's experiences over time. Narratives of HIV illness experience are often woven into other narratives related to pre-migration, migration and settlement (Ndirangu & Evans, 2009). In this study, I found that each participant's narratives of HIV illness shifted from a focus on symptoms and treatment, toward experiences of HIV in the context of life narratives such as living and integrating into Canadian society. This phenomenon is something that Wong, Li, Poon, and Fung (2013) also found in exploring the mental health of immigrants living with HIV in eastern Canada. Immigrants and refugees living with HIV composed narratives of experience related to (under/un) employment, access to community supports, unstable housing conditions, changes in socio-economic status, and settling into their new host country (Wong et al., 2013). During the time that I lived alongside Lesedi, Rita and Sifa, I often heard that their HIV "is okay" and each participant focused on their multiple life narratives rather than a singular narrative of HIV illness.

Also, each participant described the experience of living well with HIV in Canada and positioned these narratives alongside narratives of what they imagined their lives would be if they were living with HIV in Africa. Interestingly, each participant spoke of how difficult their lives would be if they were still living in their home countries with HIV. They also suggested that they would likely not live well with HIV if they remained in their home countries. This is unique to African immigrants living with HIV in Canada. Narratives of living with HIV among Lesedi, Rita and Sifa were often told in relation to narratives of past and to the mundane stories (Crites, 1971) of their home countries.  Imagining what life would be like ‘back home’, Lesedi, Rita and Sifa talked about the challenges of living with HIV in Africa and accessing HIV treatment, care and support in these countries, which are well documented in the literature (UNAIDS, 2012).  Although much progress has been made to scale up access to HIV treatment programs in African countries, many challenges remain for people living with HIV in Africa (UNAIDS, 2012).  Lesedi, Rita, and Sifa, as African immigrants living with HIV have unique experiences of HIV illness in comparison to their Canadian-born counterparts.  Their narratives of living with HIV in Canada will always be told in relation to the mundane and scared stories (Crites, 1971) they carry from their home countries.

Each story composed is in some way a creation story (Crites, 1971). Stories told in the present are stories brought into consciousness (sacred stories), in relation to mundane stories (Crites, 1971).  For Lesedi, Sifa, and Rita, experiences of living with HIV, told through stories, were not only about living with HIV, but rather about sacred stories that came alive in their consciousness alongside the mundane stories that lived within each of them.  Expressions of mundane stories bring a sense of reality for people, but being awake to one’s sacred stories brings a narrative form of identity (Crites, 1971; Huber et al., 2004).  During this study, I found that the experience of living with HIV was always told in connection to multiple stories.  Understanding Rita’s stories to live by, including being raised in the Catholic religion, were important stories related to her identity in the present time and to how she made sense of her world as an

African woman living with HIV in Canada. For years after her HIV diagnosis, Rita lived with guilt about her positive HIV status. Her story to live by as a Catholic shaped the immediate years after her HIV diagnosis. Rita often blamed herself for her HIV infection, believing that perhaps she did something immoral to have contracted HIV. Religious and spiritual beliefs are closely connected to how HIV is understood among African peoples (Chatindo, 2011; Denis, 2011; Kamau, 2011; Ndirangu & Evans, 2009; Olivier & Paterson, 2011). Kamau (2011) described:

> In many African cultures, it is a common belief that good human conduct is rewarded by the spiritual world with abundant rainfall, plentiful harvests, offspring and general prosperity, while adverse conduct is punished with disease, epidemics, famine, drought and even death. Given this reality, understanding people's culture has been deemed critical in informing appropriate ways of handling [HIV]. (pp. 257–258)

Further, both traditional and non-traditional (e.g., Christian) religious beliefs shape people's understanding of how or why HIV is transmitted, as well as how people view others who are HIV-positive (Chatindo, 2011; de Gruchy, 2011; Denis, 2011; Kamau, 2011; Ndirangu & Evans, 2009; Olivier & Paterson, 2011). De Gruchy (2011) described key issues central to the praxis of the church in relation to HIV and AIDS, one of which relates to how faith communities view sexuality, morality and immorality. The implication of such issues is that the HIV infected person is viewed as someone who is guilty of immoral sexual misconduct

(Denis, 2011). Further, Ramirez-Johnson and Hernandez (2005) described faith-based organizations as “sleeping giants” (p. 105) that sometimes pass harsh moral judgments towards people living with HIV. This can have profound impact for people living with HIV, including exclusion, stigma and discrimination. For Rita, being raised as a Catholic was only one of several stories that Rita lived by that shaped her identity following her HIV diagnosis, her identity today, and her identity into the future.

Rita also lived familial and cultural narratives, which will also continue to shape her. For example, Rita’s story continues to unfold as her father’s daughter. Greeff (2013) discussed two broad views related to family and culture which can shape family responses to a family member living with HIV. Collectivism and individualism can influence relationships within families (Greeff, 2013; Kagitcibasi, 1997). A family that values collectivism may also value social morality and loyalty, while a family that values individualism may value individuals’ wills and interest (Kagitcibasi, 1997). Rita’s family likely valued collectivism. Social morality of the family unit became evident in Rita’s composed narratives from adolescence:

> “I was 15 when I had my daughter and I was 16 when I had my son. I was too young to have them. But I know it is a sin to end the pregnancies so I had them. When I had my daughter, they took her. I never held her. I never breastfed her – *nothing*. My family, they said, ‘She’s not your baby. Don’t tell anyone’. It was such a stigma for me to have babies that young

> . . . You know, I brought shame for the family at that time. I brought two kids to this world. My grandma lied to everyone. They didn't tell anyone they were my kids. I didn't tell anyone about my kids. I listened to my grandparents.

Rita's narratives of having children at a very young age, and outside of marriage is an example of how these events challenged the collectivism within Rita's Catholic family. The shame she felt during this time in her life was connected to the social and moral expectations of her family and Catholic community.

Also, Rita's relationship with her father continues to be shaped by her HIV-positive status. Her father's response to her HIV illness reflects his feelings of shame towards her and the significant stigma and discrimination the illness brings to the family. Narratives of bringing shame to her father and her family continues to influence how Rita's family makes sense of her HIV-positive status:

> And my father . . . I believe he was ashamed of me and . . . he is still ashamed of me. My father was there in the hospital when I was there. I'm his first born and he was worried about me. But he wanted me to keep quiet about it – about my HIV – not to tell anyone.

Despite Rita's father pushing her away because of her HIV status, her story to live by continues to unfold as his daughter, reaching out to him and hoping to repair their parent-child relationship. Interestingly, Rita continues to be shaped by her role as a parent, through her relationship with her own children. Although she experiences tensions with each of her children, her story to live by continues to unfold as a mother to them, living openly as not just their biological mother but as their emotional mother.

The familial, social and cultural narratives that each participant shared remained important to understand their experiences. These narratives were often interwoven, forming complex landscapes that each person lived. These narratives will continue to shape and unfold their complex lives, continuing to compose who they are and who they will continue to become (Steeves, Clandinin, & Caine, 2013). People will continue to experience, to act with consciousness, and to awaken to sacred stories of experience and identity (Crites, 1971). I use the metaphor of a tree to show how narrative forms of identity are deeply embedded in complex contextual, social, cultural, and historical landscapes (roots of a tree), and how people's complex landscapes of experience and the (re-)telling of narratives give rise to future narratives of experience, continuously shaping one's narrative identity (branches and leaves of a tree). As Crites (1971) described:

> [How] we remember, anticipate, and even directly perceive, is largely social. A sacred story in particular infuses experience at its root, linking a man's individual consciousness with ultimate powers and also with the inner lives of those with whom he shares a common soil. (p. 304)

Looking at the past helps to deliberate on the present and gives way to creating new futures (Gergen, 1999). Stories of past remain important to stories of present because they have shaped stories of the present and will continue to shape stories to be told in the future (Crites, 1971; Gergen, 1999; Steeves et al., 2013). For the participants of this study, it was clear that stories of childhood, family, and relationships were important in shaping their narrative identities. For Lesedi, the narratives he composed of himself were tied to his familial narratives, specifically his relationship with his mother and his (lack of) relationship with his father. It became clear over the time I lived alongside Lesedi that familial narratives intertwined intimately with social and cultural narratives and will continue to weave into his identity and lived experiences. I also think about how Lesedi bumped up against stories of being gay in Uganda. Lesedi once said:

> I found myself in a society that was like Ghana . . . I thought I was starting a new life but it's just the same. People there believe that being gay is wrong. People teach their children at a young age that this kind of behavior is wrong and people make children believe it. That is what happened to me. I knew I was different at a very young age. But I would never be able to identify this way because my family said things, did things to say 'that is wrong', that I'm not quite right. There's so much stigma about being gay and being a sexual minority. In my country or a country like Uganda, there is no help for people who struggle with their identity.

In Ghana, Lesedi grew up in a family where being gay was not accepted. In his narrative accounts he spoke about the experiences of family exclusion related to who he was becoming as a young gay boy. Although Lesedi fled his home country of Ghana to find acceptance as a gay man in Uganda, the social views of gay men in Uganda eventually forced Lesedi to flee that country. Political and social hostility towards homosexuality are endemic to sub-Saharan African countries (Smith, Tapsoba, Peshu, Sanders, & Jaffe, 2009). However, Uganda has been described as an active persecutor of homosexuals (Dicklitch, Yost, & Dougan, 2012). In 2009, a Ugandan member of parliament proposed anti-homosexuality legislation, calling for the death penalty on homosexuals and imprisonment for those aiding homosexuality (Uganda Gazette, 2009). Lesedi experienced discrimination, harassment and fear as a result of this proposed legislation while living in Uganda and these experiences continue to shape his identity today as a gay man living in Canada. Each story Lesedi composed of exclusion and discrimination brought new interpretation and meaning to what this meant for Lesedi and his identity over time. I recall a story that Lesedi shared from childhood and his expression while he told me this story. When he spoke of his mother, he spoke with a smile, but when he told stories of his father and male relatives, he spoke with a certain sadness. One time Lesedi said:

> My mom and I, we had a very special bond that just developed. I always heard stories about when I was a baby, I just clenched on to my mother. We were so close. I would even push my little brother away if I saw him near my mother. Anywhere she went, I was always with her. When I was with my mother, I always felt I was with my friend. But not my father. I always felt insecure when I was with my dad – like I'm not at his level. But with my mom, I never felt insecure . . . Sometimes, my uncle would

> try to pull me away from my mom's side because he said it's not good. In our culture, they want the boys to bond with the uncles and the dad.

As I lived alongside Lesedi, I saw that the stories Lesedi composed of his childhood continued to unfold later in his life. Lesedi talked about the process of self-acceptance of his sexual identity:

> When I was growing up, there were times that I felt like I disappointed my mom. And then there were times when I thought *'Okay, I have to live life for me, not for her'*. I've tried so many times to change my sexual orientation and to become more like a man. And now - I know it's something that I can't change. I've I accepted that now. But it was very difficult for me to accept. I had to struggle with it . . . *really struggle with it.*

It took Lesedi many years and much reflection to come to terms with his identity as a young gay man. I also learned that place was significant in Lesedi's search for self-acceptance. He told stories about moving away from home, from the isolation he felt in his family and community, in search of himself as a young gay man. In many ways Lesedi continues to live out his life, re-telling stories of past and creating stories of present. In this sense, Lesedi's stories are never final (Bamberg, 2011) as he continues to live in the midst of transition, always in the state of becoming (Bamberg, 2011; Greene, 1993). For Lesedi, his state of becoming may continue to be filled with uncertainty because of the way his stories continue to bump up against each other as a gay man living with HIV and how his relationships with his mother continues to unfold with uncertainty.

For Sifa, she often composed narratives of herself as a person (dis)placed from her home in Rwanda. Narratives of hardship, suffering and surviving harsh emotional and physical conditions were often intertwined in her stories. Sifa continues to live her life in the midst of transition, her life unfolding in a way that still connects to her life in the Tanzanian refugee camp where she once lived. Sifa experienced extreme trauma, both physical and emotional, as a young person and as an adult. However, it seemed that as she moved from one geographic space to another it was to seek a sense of peace and safety, not necessarily to find a new moral space to redefine her stories to live by. She often moved to leave behind violence and danger. In this sense, her movement across borders was intentional to leave behind a particularity (MacIntyre, 1981). This was apparent when Sifa and her children moved from the refugee camp in Tanzania to Canada as refugees. By crossing international borders, it meant that Sifa could indeed physically leave her old life behind and metaphorically find a new place of becoming for her and her children. Crossing borders and leaving one geographic space was necessary for Sifa and her children to leave a ‘found community’ (Lindemann Nelson, 1995) in order to search for a ‘chosen community’ (Lindemann Nelson, 1995) in their new geographic space of Canada. I do not want to stop at the notion that Sifa left her country and her painful life experiences behind in Tanzania in order to start a new life in Canada. I believe that like Lesedi and Rita, Sifa did not leave behind her stories to live by. It is true that Sifa left behind a physical space where she experienced poverty and physical and emotional abuse. And though she left a physical space that significantly shaped her stories to live by, I believe she carried them with her as she left Africa and settled in Canada. Her past experiences and stories to live by continue to shape her life and life experiences in Canada; they continue to shape stories to live by even though she no longer lives in the moment of such painful experiences. One time Sifa talked about her current life in Canada in relation to her life in Tanzania. She said,

> They're [my kids] going to be good. They're here. Because back home, it's not easy for refugee camp. You don't have . . . No family. If I pass away there, nobody going to take care of kids. They're going to go like, outside. But this Canada, they're going to, Canada, they're going to take care of them . . . When I come to Canada I was very sick. Now I'm okay. My kids, okay. They're going to be good if I die today.

In this sense, Sifa's experiences of her present life in Canada are shaped by the experiences she left behind in Tanzania. When Sifa composed narratives of her experiences in Canada, they were told alongside her narratives of life experiences in Tanzania. It is what MacIntyre (1981) described as the notion of moving forward from a 'particular'. That is, the narratives that Sifa composes of herself today are often told in relation to the narratives she composed of yesterday, her life in the Tanzanian refugee camp. This is also what Crites (1971) described as our ability, as conscious beings to tell stories of experience, mundane and sacred, and to connect these stories to help make sense of present reality and identity.

#### ***Searching for narrative coherence.***

To understand narrative coherence it is important to acknowledge that stories to live by are continually evolving over time and place (Huber et al., 2004). The search for narrative coherence is a continuous unfolding process, where individuals use narratives to make meaning about their life and stories to live by (Bhatia, 2011; Huber et al., 2004). Carr (1986) described narrative coherence as a fragile achievement, a process of

> telling and retelling, to ourselves and to others, the story about what we are about and what we are . . . narrative coherence seems to be a need imposed on us whether we seek it or not. Things need to make sense. (p. 97)

The search for narrative coherence is a way of searching for meaning in one's life. In this continually unfolding way of finding meaning, I found over time with Lesedi, Rita, and Sifa that there were several expressions of narrative coherence (Huber et al., 2004). For example, over the time I spent alongside each participant, I found that they told stories of resistance, stories that bumped up against each other, stories of family, culture and spirituality. Lesedi, Rita and Sifa composed stories about childhood, belonging, acceptance in their families and their communities, and living with HIV, all of which intertwined and unfolded over time in the search for narrative coherence. Stories that were "left out"

(Bamberg, 2011, p. 5), or silent stories also have a place in the search for narrative coherence. After living in relation with Lesedi, Rita and Sifa, I realized that there may be many stories that were untold, or stories that remained silent. Lesedi was the only participant who spoke of experiences with traditional medicine practices as a child, while Rita and Sifa never spoke of such experiences. Also, Lesedi rarely spoke of his relationship with his father or perhaps the absence of a relationship with his father. Sifa too had silent stories about the relationship she had with her siblings after she fled Rwanda and lived in a Tanzanian refugee camp for many years. And though Rita always remained open to sharing "anything," she too likely had stories that remained silent. Such stories, though silent, remain important to one's search for narrative coherence. Stories composed for telling and non-telling, chosen or not chosen, brought to consciousness or not, still remain important in narrative coherence and must be attended to in making meaning in one's life (Bamberg, 2011).

In co-composing narrative accounts with Lesedi, Rita and Sifa, many stories were told and re-told about life experiences as children, young adults, and experiences in the present time, as people living with HIV. Stories told took place in several geographic spaces for each participant before finally arriving in Canada as immigrants: Lesedi as a refugee applicant, Rita as an immigrant reuniting with her biological father, and Sifa as a government-assisted refugee. The notion of place intertwined with Lesedi's, Rita's and Sifa's search for narrative coherence, their search for meaning in their life. Many times, Lesedi, Rita and Sifa talked about what their lives would be like or how they would be, if they had not left their home countries. Rita, for example told stories of how fortunate she was to be in Canada and to receive her HIV care and support in Canada. She often composed stories of what her life would be like in her home country of Ethiopia. Rita would often say, “I wouldn’t be alive today.” Lesedi too spoke of how geographic space continues to shape who he is and how he searches for narrative coherence. While composing stories of discrimination and stigma, he described the stigma he felt in Uganda as “just the same” as the stigma he felt in Ghana. He also shared that he had hoped to feel less discrimination and stigma in Canada, but did not experience this when he left Uganda.

When I reflected on the time I spent with each participant, I learned that Lesedi, Rita and Sifa each had lives filled with significant life experiences all intertwined together to form complex life narratives. Stories to live by were often uncovered through deep conversation with Lesedi, Rita and Sifa; these were the roots of their experiences. The narratives of past experience help to understand a person’s stories to live by (Habermas & Paha, 2001). Life narratives were told and retold over time, and it was over time that I began to understand each participant’s stories to live by, understanding their identity through being in relation with them.

#### ***Living in the midst (of transition).***

Living in the midst is what Clandinin and Connelly (2000) described as locating ourselves along the dimensions of time, place, and the personal and social. That is, people are “nested within a set of stories” (Clandinin & Connelly, 2000, p. 63), in time, in place and in relation to ourselves and to others. Further, people are always in the process of becoming and evolving in time and in place (Clandinin & Connelly, 2000). When I entered into the lives of Lesedi, Rita and Sifa, I met each of them in the midst of their lives. Their lives were “shaped by attending to past, present, and unfolded social, cultural, institutional, linguistic, and familial narratives” (Clandinin & Caine, 2013, p. 170). When I think about Lesedi, Rita and Sifa, and the time I spent with each person, it became clear to me that their life narratives continued to unfold, never ending and always changing over time. There will never be a final story. At the end of our formal research relationships, their life narratives continued along the path of time, place, the personal and social (Clandinin & Connelly, 2000), always open to new possibilities and interpretations (Greene, 1993).

Greene (1993) wrote about the inevitable social landscapes people live in and suggested that people must exist alongside other people, to interact and share in the human relationship. She described this relationship as one where people relate to one another, “in the process of choosing, of becoming what that person (in the midst of others) is, not yet” (Greene, 1993, p. 219). Here, I think of Rita and the necessity to live in multiple ways, through multiple narratives in order to bring a sense of coherence to her life narratives. Rita often spoke about her life nested in the landscape as a committed Catholic woman. This provided a landscape to other narratives in her life, namely the tensions she experienced with members of her family, as well as her spiritual relationship with God after she was diagnosed with HIV. Rita often spoke about stories that bumped up against each other throughout her life. For example, as a child, Rita described how her experiences of curiosity bumped up against her story to live by, shaped by her Catholic upbringing:

> For some reason, when I was young, if someone said 'Don't do it', I will do it anyways. I still have that kind of a habit today. I remember when I was a little girl . . . my grandparents never explained why I shouldn't do certain things. They would just say that I would go to hell if I didn't listen. I am a Catholic. I still believe in God . . . They would often say 'Don't do it or else you will go to hell' - that's the Catholic way . . . So when my grandparents said 'Don't do it', I just did things I wasn't supposed to do anyway.

Even as a young child, Rita's story to live by as a person of the Catholic faith often bumped up against other stories she lived by: curiosity, testing boundaries, and exploring things even if it caused tension within her life. When Rita had her first two children as a teenager, she spoke about these counterstories (Lindemann Nelson, 1995), stories about resisting her grandparents' authority: "They don't teach you how to use protection or birth control. These are not allowed in the Catholic Church."

When Rita was diagnosed with HIV in 2003, her life became very complex. Her HIV diagnosis had complicated Rita's life, her relationships with family members, friends, and her spiritual relationship with God. Rita often talked about the experience of living day by day, only in the present and never in the future. In fact, during our time together, Rita realized that nearly 10 years had passed since her diagnosis, and she was in near disbelief that she had lived day by day for many years. For Rita, living with HIV had imposed a life of living in the midst of uncertainty, of not knowing how her life would shape and unfold as a person living with HIV.

Rita lived her life in the midst of many uncertainties and continues to live in this midst. Her relationship with her family, specifically her father became strained and full of uncertainty after her HIV diagnosis. In this sense, a life of uncertainty fits with the notion of people always becoming and always in the making (Greene, 1993). As Greene (1993) wrote:

> [People] are creating meanings, becoming in an inter-subjective world by means of dialogue and narrative. [People are] telling their stories, shaping their stories, discovering purposes and possibilities for themselves, reaching out to pursue them. (p. 213)

But it seemed that Rita’s life, over time, had been full of uncertainty and therefore always unfolding. When she gave birth to her children as a teenager, she was forced to live with a secret for many years. Her grandparents kept her children away from her and her pregnancies were kept secret from her community and family. Rita composed stories of living in secrecy, keeping secret her children and her role as a mother. For Rita, living in secrecy meant living in the midst, becoming and discovering her self in the midst of secrets and other unknowns. When Rita was an adult, she learned that her parents were in truth, her biological grandparents who adopted her; that her mother died when she was a young child and that her biological father was still alive. At this juncture in her life, she searched for her father and eventually reunited with him in Canada. They began their newly discovered father-daughter relationship. However, at the time of her HIV diagnosis, her relationship with her father shifted again, turning towards estrangement. At the same time Rita was reunited with her children, this time as their mother, not just as their biological mother, but as their emotional and relational mother. However, this relationship was also strained because of the events and timing of her HIV diagnosis. When I look at Rita and her life, there were many complexities surrounding her life as a person living with HIV. I think about the stories Rita composed of herself and her life, and how deeply rooted these stories are in a web of experiences. Today, she continues to live her life, in the midst of uncertainty, together with her longtime partner. Rita's life will continue to unfold, and she will continue to create new meanings and understandings of her identity, her stories to live by.

Lesedi, like Rita, continues to live in the midst of transition. His stories to live by come from years of familial pressure to live his life the way his family expected him to. Lesedi said:

> In our culture, they want the boys to bond with the uncles and the dad. But when I'd go with my dad and my uncle, I didn't feel comfortable. I

> would get so upset and I would cry. *I would cry, I would cry.* I always wanted to be with my mom.

As a young boy, Lesedi experienced family exclusion, which played out in the later years of his life, shaping experiences of stigma and discrimination in other social landscapes. Although his experience of exclusion and discrimination were present throughout his life, listening to and learning about his experiences helped me to understand and make sense of the different plot lines that shaped his identity, an identity that shifted in response to these plotlines (Bach, 2007).

#### Found and chosen communities.

Over time Lesedi, Rita and Sifa, seemed to have found physical and social places to call home, at least for now. I use the word home very broadly to capture not only the physical places of settling, but also the emotional and social places of finding and settling into communities. Fortier (2001) described ‘home’ as not necessarily a place of origin, but rather a destination. In this sense, ‘home’ is a place where one travels to, to find belonging and acceptance, and in this journey of finding ‘home’, identity and the process of becoming are shaped. Fortier (2001) also described the interaction between migration, belonging, and ‘home’. In the journey of finding ‘home’ it is not necessarily about moving from one place to another, or about thinking ‘home’ as mobile (Fortier, 2001). Rather, migration can be seen as the journey of re-forming the bounded spatiality of ‘home’ (Fortier, 2001, p. 407). ‘Home’ then becomes not just a physical place, but a moral, emotional and social destination to find belonging, acceptance and identity. In the same way that Fortier (2001) described the notion of ‘home’, I use the word ‘community’, and in the way Lindemann Nelson (1995) has:

> Community as particular social and personal contexts from which the self takes its identity. It is the place where significant human relationships and human situatedness takes place. (p. 23)

Places like ‘home’ and ‘community’, then, are places that encompass the physical, social, emotional, and moral. I also use this term to suggest that the process of settling is truly never ending, that there is inter-lapping between the notion of narrative coherence and found and chosen communities. That is, that one’s life experiences and telling and re-telling narratives continue to unfold into the future, always shaping stories to live by.

Lindemann Nelson (2001) described two types of communities, found and chosen, based on Friedman’s (1989) work. Communities into which we are born into and reared into are described as found communities (Friedman, 1989; Lindemann Nelson, 1995; Lindemann Nelson, 2001). Found communities may include families, neighborhoods and nations, and are seen as important factors building one’s identity and moral space (Lindemann Nelson, 2001). Found communities are often communities that people have not voluntarily chosen to be part of, but rather have been born into. However, as Friedman (1989) noted, found communities have the potential to exclude and suppress some of their members. People, particularly those who have been oppressed in their found communities may search for different forms of community and may voluntarily choose to become part of such communities. These are what Friedman (1989) and Lindemann Nelson (2001) described as chosen communities. Chosen communities are those that individuals choose, those which foster acceptance and provide a context of re-negotiation of self-identities (Friedman, 1989). Boundaries between found and chosen communities may be blurred, however each type of community is distinct from the other (Lindemann Nelson, 2001). A found community operates on a set of moral understandings that have been already developed and provided to its members, whereas chosen communities operates on moral understandings that have been re-created or re-negotiated by their members (Lindemann Nelson, 2001). Within a chosen community, stories that Lindemann Nelson (1995) described as counterstories can be found. Counterstories are “stories that contribute to the moral self-definition of its teller by undermining a dominant story, undoing it and retelling it in such a way as to invite new interpretations and conclusions” (Lindemann Nelson, 1995, p. 23). Counterstories are continuously told across time and place, and this telling never ends. The purpose of counterstories is to resist an oppressive identity and to (re)negotiate an identity that brings respect and acceptance (Lindemann Nelson, 2001).

I am drawn to the notion of found and chosen communities because the concept reminds me of the life narratives told by Lesedi, Rita and Sifa. Rita’s stories of experience were very much shaped by found communities, and chosen community (Lindemann Nelson, 1995). Rita’s narratives had woven within them a dominant thread relating to her spirituality and Catholic upbringing. Rita's counterstories (Lindemann Nelson, 1995) often bumped up against the stories she lived by, those connected to her found community (Clandinin et al., 2010). The dominant, "found community of place" (Lindemann Nelson, 1995) refers to the larger moral community that Rita lived in, and where many of the stories she lived by as a child and young adult were experienced. Friedman (1989) argued that found communities might exclude non-members and also suppress certain members of their community. Rita's found community included her family, which was closely connected to her spiritual community. Rita's narratives intertwined significantly and consistently with her Catholic upbringing. For example, when Rita was diagnosed with HIV, she found herself blaming herself for her HIV infection, wondering what sin she committed to deserve such punishment from God. In the area of religion, theology and HIV, there is significant focus on sexual morality and ethics in dealing with HIV. Many religions, including Christian faiths, focus on sexual morality and ethics when examining HIV and AIDS (Manda, 2011). More specifically, religious communities often view HIV and AIDS as a punishment from God (Denis, 2011; Manda, 2011) and believe that the primary way to deal with HIV is to return to the moral teachings of one's religion (Manda, 2011). Through her stories of experience, the significance of being Catholic was clear. When Rita described her experiences of coming to terms with her HIV illness, she said,

> I was mad at God. I would say: *"Why me? I pray . . . I go to Church . . . why did you do this to me, God?"* I even felt like I was being punished for something . . . Back in Africa, HIV is like a curse. People think you get HIV because God is punishing you. So I felt like I was being punished.

Rita's story to live by as a Catholic unfolded when she learned of her HIV infection. Over time however, Rita began to tell a counterstory to the dominant story she lived by. This occurred through a process of choosing her community, moving away from a found community that oppressed and blamed Rita for her HIV illness. Through re-negotiation of self-identity (Lindemann Nelson, 1995), Rita was able come to terms with, and come to a place of acceptance of her HIV infection, rather than blaming herself. This process of re-negotiation took fragments of life narratives from Rita's found community and pieced them together in a way that challenged unjust assumptions within the moral space of the found community (Lindemann Nelson, 2001). Through this process of re-negotiating her self-identity, Rita came to reconcile her self-conception of how others conceived her. That is, she was able to reconcile understandings that she had of herself and those that came from her found community. Rita shared with me:

> I think I am okay now. I'm doing good with the medications. But it is him [God] who is working and helping me. God works in his mysterious ways. It took me a long time to realize he is not punishing me and to say

> *"I'm sorry God; it's not you who gave this to me."* I know that I am okay; that *I will be* okay. I don't blame God anymore.

Rita often spoke about her work in the community as an advocate for HIV prevention, including safer sex messages and the use of condoms. I found this story particularly interesting as it bumped up against (Clandinin et al., 2010) her stories that she lived by as a Catholic woman. I wondered how Rita saw the interplay between broader Catholic beliefs and access to condoms and sexual health education. I also wondered how she made sense of these conflicting interests. It is here that the notion of chosen communities (Friedman, 1989; Lindemann Nelson, 1995) plays an important role in reconciling conflicting stories; stories that bump against stories to live by (Clandinin et al., 2010). Perhaps people with stories that bump up against each other seek a moral space which allows for the (re-)creation of moral self-definition (Lindemann Nelson, 1995). That is, by finding a moral space in which a person can search and reflect on their stories to live by:

> They do this [finding a moral space] by reviewing their personal history, weighing the particulars of their past in terms of more general moral values, and discerning a course of action which expresses a commitment to those particulars. The person will either ratify [their] history and remain on [their] present course, or repudiate it and chart a new course. Either way, [they] create a moral track record that commits [them] to certain values for the future. (Lindemann Nelson, 1995, p. 27)

Although their stories and lived experiences are unique and set apart from one another, Lesedi, Rita and Sifa each moved from their respective found communities, to search for chosen communities (Lindemann Nelson, 1995). I believe that Lesedi, Rita and Sifa continue to search for chosen communities, communities that are non-precarious. Much like the search for narrative coherence, the search for chosen communities is a continually unfolding process for each participant. Further, it is an attempt to find narrative coherence, finding sense and meaning behind one's identity and self. For Lesedi, he continues to search for his chosen community, a place and a moral space where he can find acceptance and a sense of respect from others as an individual and as a young gay man, despite his found community. For many years, Lesedi lived within a found community that continues to exclude him today. He continues to live in his found community through his relationship with his family, his mother, albeit broken for the time being, and within a non-relationship with his father. It is unlikely that Lesedi will permanently leave his found community, for individuals cannot separate themselves from their social and historical landscapes.

Sifa, for now, has settled in a chosen community in Canada, a moral space in which she lives with her children. I found, through Sifa's narratives, that she too told counterstories (Lindemann Nelson, 2001). Over time, as Sifa shared her life narratives with me, I began to recognize fragments of her life narratives that had shaped her stories to live by in Africa. Placing these fragments of narratives alongside her life narratives in Canada I also began to uncover a counterstory, one that bumped up against Sifa’s stories to live by as a woman living with HIV in Africa. Nestled within stories of oppression, Sifa composed stories of her found community, a moral space that was overwhelmed with stories of being a marginalized and suppressed woman. Sifa’s life narratives about her life in Tanzania, were often composed around issues of gender, where being a woman played a significant role in her experiences of extreme poverty, physical, sexual and emotional abuse. Gender-based inequities can negatively influence women’s health and their life experiences (Wingwood & DiClemente, 2000) and Sifa was no exception to this. The impact of the HIV pandemic on women and gender analysis of HIV is well documented (Mehta, 2006). Women who experience poverty and have limited formal education are placed at a higher risk for HIV infection (Mehta, 2006; Mill & Anarfi, 2002). As I lived alongside Sifa, I began to see how her stories to live by continue to unfold against those she composed of her stories to live by in Africa. Her life unfolded against this backdrop. Although Sifa and her children moved to Canada as part of a government sponsored refugee program, I believe she consciously began to move away from her life of dire poverty and desperation. In this sense Sifa has not completely abandoned the stories she lived by through her childhood in Rwanda and young adult years in Tanzania. Rather, these stories continue to live, unfold and shape her identity as an African woman living with HIV in Canada, and will continue to unfold in her future. Further, the impact of relocation and the social support she received as a refugee in Canada continues to shape Sifa and her search for a chosen community

(Lindemann Nelson, 1995). Being in a society that supports its people, regardless of sex or education level has played a role in Sifa's search for a chosen community. In the same way, being in Canadian society has moved Sifa away from the found community (Lindemann Nelson, 1995) that oppressed her for many years of her life. Sifa once said, "I be okay because I'm here now, this Canada." In this statement, Sifa was referring to the ways she was able to move away from years of oppression because of her gender, poverty, and lack of formal education.

Each person who participated in this study experienced movement away from their home countries or places of birth, and eventually settled in Alberta, Canada. As I reflected on the idea of moving across borders, carrying one's stories to live by, I began to understand how this movement shapes one's stories to live by. I also began to realize that physical space played an important role in each participant's stories to live by. It's as if the physical space between two geographic places created a metaphysical boundary, a boundary that acted as a place to leave stories of oppression and exclusion and to seek new experiences of inclusion. Perhaps it is this boundary that also allows for the creation of counterstories, an opportunity to make moral sense of something (Lindemann Nelson, 2001) or perhaps an opportunity to search for narrative coherence. For example, Lesedi spoke about his experience of stigma and discrimination related to his sexual identity as he moved within Africa and then eventually to Canada. When he moved to Uganda from Ghana, he talked about how he thought he would start a new life, away from the discrimination he experienced in his home country Ghana. But as he described to me, “I found myself in a society that was like Ghana . . . I thought I was starting a new life [in Uganda] but it’s just the same.”

Even when Lesedi moved from Uganda to Canada, he composed stories of feeling similar discrimination, as if the experience of discrimination and stigma travelled with him across boundaries. In postcolonial literature, “diaspora has become an emblem of multi-locality . . . and non-linearity of *both* movement and time” (Fortier, 2001, p. 406). Diaspora then raises questions about belonging, community, continuity (Fortier, 2001), and new geographies of identity (Lavie & Swedenburg, 1996). New geographies of identity relate to the non-singular relationship that migrants have with their places and across borders – their places that they currently occupy and the places they have occupied in the past (Lavie & Swedenburg, 1996). For Lesedi, the notion of leaving behind one’s story to live by in one physical place, to create a new story to live by in another physical space, was painful and difficult. Often a person cannot completely leave behind their found community, as found communities are places where social relationships provide a morally normative legitimacy (Friedman, 1989). Rather, the self, or person is “constituted and defined by their attachments, including the particularities of its social relationships, community ties, and historical context” (Friedman, 1989, p. 276). Further, Friedman (1989) described the ‘self’ as one who is able to choose one’s community. A community of choice is a place, more specifically a moral space, where one locates their self to tell self-defining stories (Lindemann Nelson, 1995; Friedman, 1989). For Lesedi, his movement from one geographic space (i.e., Uganda to Canada), though not freely done, was also an opportunity to search for narrative coherence. Through his telling and re-telling of his life narratives, I learned that Lesedi continued to search for narrative coherence by making sense of his found community and the need to search for a chosen community; by finding a new moral space in which he could (re-)negotiate the stories he lived by. However, as Lesedi shared his life stories, it was clear that his experiences of stigma and discrimination stayed with him, despite moving across borders[12]. He continues to search for inclusion and acceptance, specifically within his familial stories. Despite his attempts to find a new moral space, a place to locate himself as a person and to re-create (new) stories to live by, Lesedi experienced challenges in doing so. Perhaps his dominant story to live by, his story of being othered in an exclusionary way (Canales, 2000) as a young gay man continued to play out strongly even as he crossed many borders and entered into new societies. As MacIntyre (1981) stated, “one’s moral quest must begin by moving forward from a particularity for it can never be simply left behind” (p. 205). “Particularity”, in this sense is referring to one’s moral starting point (MacIntyre, 1981, p. 205), one’s social, cultural and community history.

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[12] HIV-related stigma and discrimination is pervasive in African countries and even with interventions to reduce HIV-related stigma, the experience of stigma and discrimination may decrease, but may never be eliminated entirely in the long term as discussed in Chapter 3. In Lesedi’s experience, I found that his experience of stigma remained with him, over time and across geographic, political and social landscapes.

### Narrative interlappings.

Narrative interlappings (Huber et al., 2004; Sweetland, Huber & Whelan, 2004), is conceptualized as a complex process of storytelling, response, understanding and making meaning of stories to live by. Narrative interlappings is also related to the search for narrative coherence, telling and retelling stories of who we are and who we are becoming in the midst of storied landscapes, landscapes which may [or may not] seem nonsensical to us (Huber et al., 2004). It is "what happens when we tell our stories in conversation or write them in narrative accounts that move across or within individuals' experiences" (Huber et al., 2004, p. 194). However, it is important to note that narrative interlappings do not take place within one individual; rather it is a relational way of being with another. That is, narrative interlappings requires a form of response within and between people in order to achieve understanding and meaning in stories to live by. Lugones' (1987) notions of "world" and "world travelling" (p. 9) are relevant to narrative interlappings. Lugones (1987) described "world" and how it relates to identity, and identity within place and time:

> ['World' is something] that may be an actual society given its dominant culture's description and construction of life, including a construction of the relationships of production, of gender, race, etc. But a "world" can also be such a society given a non-dominant construction, or it can be such a society or a society given an idiosyncratic construction . . . In a "world", some of the inhabitants may not understand or hold the particular

> construction of them that constructs them in that “world”. So, there may be “worlds” that construct [one] in ways that [one] does not even understand. (p. 10)

As I reflect on Lugones’ (1987) notion of world in relation to identity, I am reminded of Lesedi and Sifa. Though Lesedi and Sifa each composed unique life narratives and stories to live by, they were deeply impacted by their respective worlds, worlds that they once belonged in their home countries in Africa and worlds that they now live in Canada. In Lesedi’s narrative accounts, Lesedi talked about how he thought his life would change in Canada, leaving Ghana and Uganda, and the discrimination and stigma he experienced as a young gay man. However, in his narratives he described feeling “the same” in Canada as he did in Africa. Interestingly, Lesedi himself expected that his ‘world’ would change, specifically by not having as many experiences of discrimination and stigma. As Lugones (1987) stated:

> The shift from being one person to being a different person is what is called “travel”. This shift may not be willful or even conscious, and one may be completely unaware of being different than one is in a different “world”, and may not recognize that one is in a different “world.” (p. 11)

In Lesedi’s experience, travelling form one world to another may not have been done willfully. But when he reflected on his travels from his world in Africa to a new world in Canada, he felt “the same.” That is, when he arrived in Canada, he continued to live out his life as a gay man, facing challenges of stigma and discrimination.  For Sifa, I think about her life narratives and how these unfolded and shaped her stories to live by.  What I found most interesting about Sifa was how she composed stories of herself living with HIV in Tanzania compared to how she composed stories of herself living with HIV in Canada.  The stories Sifa composed were in contrast to one another.  In Tanzania, she lived with HIV secretly from others; with the exception of one friend, who themself was living with HIV, she told no one of her diagnosis.  Sifa composed narratives of fear: fear of being rejected by those around her, fear of her children being isolated in their school, and fear of being marked as someone who did something “bad” to have contracted HIV.  Yet as Sifa composed narratives of herself living with HIV in Canada, they are remarkably different[13].  Her ‘travel’ into another ‘world’ (Lugones, 1987) shifted Sifa’s stories to live by as a woman living with HIV.  In Canada, Sifa was very open about her HIV illness and there seemed to be less fear of being labeled as a “bad” person, less fear about seeking HIV treatment and support, and more importantly, less fear about being excluded by others who might know about her positive HIV status.  Though Sifa seemed to live a very private life in Canada, she was open about her HIV status with her previous partner, friends and her children.  This is something that shifted for Sifa, as she travelled between two worlds (Lugones, 1987) carrying her stories to live by.

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[13] In the experiences of Lesedi, Rita and Sifa, stigma and discrimination were very pervasive in their lives.  However, it was particularly interesting to see how the experience of stigma and discrimination changed in different geographic, political, social and moral landscapes. Experiences were unique for each participant. Lesedi, for example continued to live secretly with his HIV in Canada, whereas Sifa lived less secretly about her HIV when she moved to Canada.

Lugones (1987) also described the notion of “world travelling” (p. 6) as a way to see the experience of others: “world-travelling . . . is a skillful, creative, rich, enriching and loving way of being and living” (Lugones, 1987, p. 3). Further, it is a way of being in the midst of another person, in a relational way. To illustrate, Lugones (1987) shared her reflection of her relationship with her mother, travelling into her mother’s world:

> Loving my mother also required that I see with her eyes, that I go into my mother’s world, that I see both of us as we are constructed in her world, that I witness her own sense of herself from within her worlds. Only through this travelling to her “world” could I identify with her because only then could I cease to ignore her and to be excluded and separate from her. Only then could I see her as a subject . . . and only then could I see at all how meaning could arise fully between us. We are fully dependent on each other for the possibility of being understood and without this understanding we are not intelligible, we do not make sense, we are not solid, visible, integrated, we are lacking. (p. 8)

Narrative interlappings (Sweetland et al., 2004) is shaped by the idea of world travelling (Lugones, 1987). Narrative interlappings is a process of “openly embracing and exploring differences, in moments of tensions, fear and vulnerability, and requires strong commitment to self and to other” (Sweetland et al., 2004, p. 49). Further, it is a relational way of being (with another) in the process of storytelling and response, something necessary in shaping narrative spaces of collaborative inquiry (Sweetland et al., 2004). In the narrative accounts of Lesedi, Rita and Sifa, I wrote and reflected on the moments I lived alongside each person, moments of living in the midst with Lesedi, Rita and Sifa. These reflections were, in part a way of response to Lesedi's, Rita's and Sifa's storytelling. The narrative accounts also reveal other ways in which Lesedi, Rita, Sifa and I lived in conversation and in response to one another - "as one story resonates with another in the telling, new plotlines in lives become visible or old plotlines are seen in new ways" (Huber et al., 2004, p. 194). It was by being in relation with Lesedi, Rita and Sifa that stories were told in conversation and overtime began to unfold meaning and narrative coherence. The process of narrative interlappings created a space where moments of tension were attended to, whether silent or not, and where narratives were told, re-told and unfolded for meaning. By "collectively honoring our embodied, narrative ways of knowing, we allow our lived stories to come forward, to circulate, and unfold through response with another" (Sweetland et al., 2004, p. 50). As I lived alongside Lesedi, Rita and Sifa, I too was awakened to many of my own memories, including memories of being a second generation immigrant child. Living in this relational inquiry space with Lesedi, Rita and Sifa made me wonder and reflect on my own stories to live by and how my stories to live by existed side by side Lesedi's, Rita's and Sifa's stories to live by. Like a world traveler (Lugones, 1987), I travelled into the worlds of Lesedi, Rita and Sifa, living alongside Lesedi, Rita and Sifa in the midst of their lives, "venturing towards uncertainties, sometimes consciously, sometimes unconsciously" (Sweetland et al., 2004, p. 50), and negotiating possibilities for narrative coherence. In the act of being and relating with Lesedi, Rita and Sifa, I too shared the experience of searching for narrative coherence in my own stories to live by. Together, we moved towards a shared intimate space where we co-composed stories of understanding, negotiation and of living in relation.

## Summary

In the process of reflecting on Lesedi's, Rita's and Sifa's narrative accounts, I began to make meaning of their narratives of experience. Lesedi's, Rita's and Sifa's narrative forms of identity, their stories to live by, began to unfold over time as we lived alongside each other during the research study. Their stories to live by will continue to unfold and shape their identity beyond their involvement in the research study. Narratives are articulated from experiences, acts of awareness, feelings, episodes which begin and end, and experiences which are composed of other experiences and combine to make up larger narratives (Carr, 1986). Meaning making of experience, making sense of things (Bach, 2007; Carr, 1986) happens over time. However, Carr (1986) argued that the relation of past experience to the present experience is not simply about the former causing the latter. Rather, that the past has meaning for the present and for the future:

> It must be remembered that in order to have experiences, [one] must have them one at a time; [that one is] always located in the now with respect to past and future experiences. (Carr, 1986, p. 27)

Living in the inquiry space with Lesedi, Rita and Sifa allowed each of us to co-compose narratives of our selves, not just telling and re-telling stories, but living our own stories (Carr, 1986). Through relationship, it is clear that one cannot be treated as if they did not exist in a social situation with another (Carr, 1986). The sociality between myself, as researcher, and each participant in this study must be taken into account because meanings of experience are negotiated and continue to shift within the inquiry space. Others are called upon to hear, co-compose narratives, and to experience expressions of narrative interlappings (Sweetland et al., 2004).

# Chapter 8: Reflective Turns

In this chapter I discuss the significance of this study by revisiting the research puzzle. I realize now, after living alongside Lesedi, Rita and Sifa, how much I have been shaped by the experience of living in the narrative inquiry space. As I wrote this dissertation I experienced several turns: a transformation of my thinking about narrative inquiry as methodology, a shift in my understanding of narrative inquiry as phenomenon, and a turn to narrative inquiry as a way of being in practice. I write about these reflective turns through the discussion of the personal, social and practical significance of this study. First, within the personal significance, I discuss narrative inquiry as both methodology and phenomenon. I discuss how my thinking and being in relation to others has transformed during and after this narrative inquiry research. Second, I discuss the social significance of the research puzzle, in terms of new theoretical insights related to migration, health, and understanding the experience of HIV as illness. Finally, in the practical significance, I discuss several considerations from a nursing practice perspective and explore how the study findings bring new possibilities for nurses in Canadian practice who provide care and support African immigrants living with HIV.

## Personal Significance

As I wrote this chapter, I thought again about my journey from the time I first began my doctoral program and chose narrative inquiry as the methodology for this study. In just a few years of intense work, reading, reflection and living alongside each of the study participants, I realized that my thinking as well as my being has changed. I experienced narrative inquiry as both a methodology and phenomenon (Clandinin & Connelly, 2000; Clandinin, 2013). As I looked back to the research proposal that guided this study, I began to appreciate the change in my thinking about narrative inquiry. For example, at the outset of the study I identified several issues (social relationships, poverty, housing, and so forth) that I planned to explore. However, I discovered while living alongside each participant that these experiences were only fragments of stories that were embedded in mundane and sacred life stories (Crites, 1971). I learned over time, that the very things that I, as a researcher, was interested in studying were not the things that each participant felt were important to their experience.

Greene (1995) described the importance of seeing big and not seeing small. I learned the importance of seeing Lesedi, Rita and Sifa in a big way. That is, over time, I learned to attend to the uniqueness of each participant, to imagine each person in their lives, seeing each person in the worlds that matter to them. It is through imagination that we make empathy possible (Greene, 1995):

> Every one of us inhabits a humanly fabricated world, is mortal and can acknowledge that mortality, and can tell the story of what happens to him or her as he or she lives…we are called upon to use our imaginations to enter into the [world of others] to discover how it looks and feels from the vantage point of the person whose world it is . . . [by doing so] we extend our experience sufficiently to grasp it as a human possibility. (p.4)

I learned by living alongside Lesedi, Rita and Sifa the importance of not seeing them small (Greene, 1995), and not having preconceived notions of what was and was not important in the narrative accounts of their lives. Instead, I began to see and understand Lesedi's, Rita's and Sifa's experiences as storied phenomena (Clandinin et al., 2010; Clandinin, 2013).

My narrative beginnings reflected a time in the midst of my own life when experiences of past and present began to shape and unfold the events leading up to my inquiry. It is what Clandinin & Connolly (2000) described as always living in the midst, that we are "located somewhere along the dimensions of time, place, the personal, and the social" (p. 63). As a researcher, I entered the narrative inquiry space with each participant, living my own stories, just as each participant entered this space living their own stories. My stories to live by as a child of immigrant parents in Canada, as a person who grew up experiencing discrimination, as a "visible minority" (Statistics Canada, 2009), as a registered nurse, nurse researcher, and as a member of my found and chosen communities (Lindemann Nelson, 1995), and the cumulative years of professional and personal experiences brought me to the research puzzle for this study. The time I spent with Lesedi, Rita and Sifa also awakened me to many memories of the stories that live within me and brought new possibilities to how I make sense of my stories to live by.

Each person I lived alongside during this study has shaped me and will continue to shape me into the future. The stories that were told and re-told by

Lesedi, Rita and Sifa are not “fixed texts” (Caine, 2010, p.1304) and will continue to be re-told “in and out of the living and in relation to others” (Caine, 2010, p.1304). That is, Lesedi’s, Rita’s and Sifa’s narratives and the experience of being in relation to each participant will continue to shape how I compose narratives of the present and future. In a way, one continues on a journey, along the dimensions of time, place and social, never arriving at the same place, but always arriving in a new place. Being in relation with another person helps to “(re-)interpret and (re-) connect my own understanding of my life experiences across time and place” (Caine, 2010, p. 1310). I am particularly struck by how each participant shaped my stories to live by (Huber et al., 2004). Lesedi, Sifa, and Rita have touched me in a way that awakened me to my own stories to live by and to the ways I seek narrative coherence in my life. Lesedi lived a cover story (Caine, Lessard, Steeves & Clandinin, 2013) for many years as a child and young boy, living out the gendered expectations placed on him by his family and his society. The experience of living a cover story impacted his relationship with his family, particularly his mother, whom he continues to dearly love despite her rejection of who he is as a gay man living with HIV. As a mother, I was struck by Lesedi’s narratives of his own mother and how his relationship with his mother changed over time, primarily based on who he was becoming as a young gay man. Lesedi once had a very close and loving relationship with his mother and over time this relationship became strained, first because of his sexual orientation and then because of his HIV positive status.

As I lived alongside Lesedi, I was awakened to memories of my own childhood and young adulthood, and my relationship with my own parents. Like Lesedi I resisted scripts (Caine et al., 2013) assigned to me by my family. Lesedi's narratives of his mother moved me; I was awakened to the parent-child relationship with my own children and the importance of composing life in a supportive and loving way with my children. I awakened to the worlds of my children and imagined their world and what matters to them (Greene, 1995). I also think about the narratives Lesedi composed of his mother and how his relationship with her made me think about Lugones' (1987) 'world travel'. I wonder how differently Lesedi's narratives of his mother would be composed if his mother saw his world through his eyes and her world through his eyes. How would Lesedi compose stories of his mother if they each travelled into each other's worlds (Lugones, 1987) and how different would their narratives be if they did so? Rita composed stories of being raised in a Catholic family. As I lived alongside Rita, her telling awakened me to my own upbringing in a Catholic family. I was awakened to my stories to live by as a member of a Catholic family and community, but also to the counterstories that I formed over time, alongside the dominant stories of the Catholic Church (Lindemann Nelson, 1995). Rita's search for narrative coherence (Carr, 1986), often brought me back to a place of my own search for narrative coherence when my chosen communities did not necessarily fit with my found community (Lindemann Nelson, 1995). Living alongside Sifa also awakened me to my stories to live by as a person whose parents are first generation immigrants to Canada. Living in relation with Sifa brought many of my own memories to my consciousness, memories related to my parents' experiences of settling in Canada, living in isolation in a new culture and finding their way to a better quality of life. What I learned living alongside Lesedi, Rita and Sifa was the "complexity of interwoven narratives, times and places when cultural, familial and institutional narratives bumped up against each other" (Caine et al., 2013, p. 243).

My experiences alongside Lesedi, Rita and Sifa will also continue to shape my "ongoing lives" (Caine et al., 2013, p. 244), always unfolding in new ways. I see this when I deeply reflect on how I have shifted in the last year of my dissertation work. As I wrote my dissertation, I realized that I am changed. Narrative inquiry was not only a methodology for this study, but it has become a way of being, of attending to other people's and my own lives. In this way of being, I am profoundly changed by the way I see others, in a 'big' way and with imagination (Greene, 1995). Engaging in narrative inquiry has become a way of being and not just doing (research methodology). Stories told and co-composed with another are "being lived and lived in being told" (Carr, 1986, p. 61). In this sense, the (re-) telling and (re-)living of storied experiences is always continuing, just as the story is never ending, but always changing (Clandinin & Rosiek, 2007).

Narrative inquiry "is an act within a stream of experience that generates new relations that then become part of future experience" (Clandinin & Rosiek, 2007, p.41). Stories of experience are told as a "result of social influences of a person's inner life, social influences in their environment, and their unique personal histories" (Clandinin & Rosiek, 2007, p. 41) and therefore are always being re-told, re-lived, and becoming in new ways. A story, "once told cannot be taken back, but instead perpetually finds ways into other stories" (Huber, Caine, Huber & Steeves, 2013, p.216). I think now about Rita, who for so many years composed stories of living day by day with her HIV illness, living in the midst of uncertainty, wondering about her mortality more than anything else. It was when we lived alongside each other and co-composed narratives that Rita discovered the meaning of living 10 years with HIV. For many years, she believed that she would not live 10 years after her HIV diagnosis. Yet, her storied experience of living with HIV, when re-told in our shared inquiry space shifted for Rita, who realized that perhaps she could start living with a renewed sense of purpose in her life and perhaps with a different uncertainty towards her mortality. In this way Rita helped me understand that in as much as I was shaped by this research our stories intersected and created a space of belonging and becoming for both of us.

## Social Significance

### HIV as a chronic condition among immigrants in Canada.

Engaging with Lesedi, Rita and Sifa in the narrative inquiry space not only shifted me in personal ways, but also in my thinking about the social significance of the research puzzle.  Going back to the study's research puzzle, I ask myself, what is my understanding of the phenomenon of HIV illness as experience? What narratives are African immigrants composing of themselves during the experience of living with HIV? What narratives are being composed about stigma, fear and discrimination? Even at this juncture of my dissertation writing, I have no clear answer except for the following: the phenomena of HIV illness as experience, lived by African immigrants is complex and intertwined with narrative forms of identity.

Several researchers (Este et al., 2009a; Este et al., 2009b; Gray et al., 2008; Lawson et al., 2006; Tharao et al., 2006), have discussed the complex social factors that shape and influence HIV illness, HIV-related stigma, and access to HIV care, treatment and support services. HIV illness has evolved to be seen as a chronic condition in many countries including low, middle and high income countries (UNAIDS, 2011). In the advent of effective HIV treatment and the rapidly expanding treatment programs globally, people living with HIV are living longer with an illness that is no longer terminal (UNAIDS, 2011). At the same time, stigma and discrimination remain present and at times form barriers to accessing testing and treatment. Therefore, it becomes important to examine HIV not only within the dominant biomedical framework, as a medically treatable and physical disease, but also to explore the counterstory to the dominant narrative of HIV treatment. That is, to examine HIV as a chronic condition nested within complex social and political landscapes. This is particularly relevant to people like Lesedi, Rita and Sifa. They often imagined with me, what their life would be like living with HIV in their respective home countries. They each felt that they would not have access to treatment or that they would not live well with

HIV because of the various political, social and cultural factors they described in their narrative accounts. Despite these concerns each participant talked about how fortunate they were to be in a country where HIV medication was accessible, and where they could live with less fear and HIV-related stigma compared to their home countries. Scandlyn (2000) described the trajectory of HIV illness as shifting from a terminal disease, to one that now bears social significance because of its chronicity. Chronic illness and the management of chronic illness bring social considerations that must be attended to (Russell & Seeley, 2009; Scandlyn, 2000; Swendeman, Ingram & Rotheram-Borus, 2009). This study has brought new insight, not just to the experience of HIV illness, but also to how HIV is lived, and shaped by narrative forms of identity (stories to live by), the search for narrative coherence, found and chosen communities, and narrative interlappings. Furthermore the findings have brought new understanding of how these narrative threads continue to shape African immigrant's illness experiences and their forward looking stories. Lesedi's, Rita's and Sifa's narratives of living with HIV were never separate from their life narratives. As I lived in their midst, I began to wonder about the relationship between one's life narratives, narrative coherence, narrative forms of identity, HIV illness, migration and settlement. Over time, it became clear to me that these aspects of experience and identity are not easily separable, but that each intimately wraps around the other, influencing and shaping the other over time and place, in the present and into the future. In this study it was clear that as each participant crossed borders and eventually migrated to Canada, their stories of past, told or untold, were carried with them and shaped their experiences of HIV illness in Canada. That is, narratives of stigma, family exclusion, and gendered experiences of discrimination were often linked to each participant's stories to live by (identity) of who they were in their countries of origin, and who they were becoming in Canadian society.

#### Carrying sacred and mundane stories across borders.

The narrative quality of experience is shaped by sacred and mundane stories of experience, as well as the temporal form of experience itself (Crites, 1971). These dimensions of experience are always intertwined with one another (Crites, 1971). The experience of HIV diagnosis and HIV illness for Lesedi, Rita and Sifa were shaped by their stories to live by and their search for narrative coherence. Further, the lives of the people they lived in relation with, their families, continues to shape the lives of each participant. Lesedi, Rita and Sifa will continue to live in the midst of transition, always in the state of becoming (Bamberg, 2011; Greene, 1993). Stories composed of the past are told as new stories, just as stories of the future will be re-invented from stories of past and present (Bateson, 1989). As Bateson (1989) described, it is near impossible for people to know what the future will hold for them and it is impossible to know what stories of the past will be in the present, as people will bring these out in the future again in new and changing landscapes. People will always continue to live in the midst of changing landscapes and as a result, experiences and stories to live by will continue to be shaped by these changing landscapes. Immigrants like

Lesedi, Rita and Sifa who migrate across borders and places will always carry with them their sacred and mundane stories (Crites, 1971). These stories are never left behind but are always with each person and continue to shape Lesedi, Rita and Sifa in their settlement experience in Canada, as people living with HIV. As an example, Lesedi, Rita and Sifa each composed narratives in relation to power or "othering" (Canales, 2000) in their home countries or countries where they last resided. Narratives of power imbalances and othering are important to consider as they continue to settle in their host country (Canada). Particularly, the vulnerability of migrants is closely linked to their experiences of power in their host country (Sabatier, 2002). Therefore, it is important to attend to sacred and mundane stories of immigrants living with HIV and to attend to how such stories continue to shape their stories to live by in their new host country.

### Living with HIV: the search for narrative coherence through found and chosen communities.

Engaging with Lesedi, Rita and Sifa, and living together in the narrative inquiry space provided new theoretical insights. More specifically there were interlappings between the search for narrative coherence (Carr, 1986; Huber et al., 2004) and found and chosen communities (Lindemann Nelson, 1995). Huber and colleagues (2004) discussed narrative coherence as a continuous, unfolding process whereby people use narratives to make meaning about their life and stories to live by (identity). There were various expressions of narrative coherence (Huber et al., 2004) that I attended to while living in midst of each participant's lives. But as I spent more time with each participant, I awakened to how each participant lived within found and chosen communities (Lindemann Nelson, 1995) and how these communities became an expression of narrative coherence. Narrative forms of identity (stories to live by) are always in motion, unfolding and changing over time and place (Caine et al., 2013). Early in my relationships with each participant, when I entered into the midst of Lesedi's, Rita's and Sifa's lives, I began to attend to their lives, unfolding at that particular moment. I began to see how places shaped their unfolding lives and stories to live by. I intentionally use a plural form of place because I believe that place in this sense refers to both a geographic place and to a moral place. I began to see the complexity of each participant's lives, in the midst of transition and how their stories to live by were being shaped by both physical and moral place. I was particularly drawn to the connection between physical and moral place, and how this connection played a role in each participant's lives. This brings new insight to the relationship between one's narrative forms of identity and how one's stories to live by are shaped by experiences of migration, settlement, and HIV illness. Basso (1996) described place making as a complex interaction of remembering and imagination:

> What is remembered about a particular place – including, prominently, verbal and visual accounts of what has transpired there – guides and constrains how it will be imagined by delimiting a field of possibilities. (p.5)

Lesedi, for example, lived out his stories to live by as a young gay man often in his found community (Lindemann Nelson, 1995) where he was rejected for his sexual identity. During his childhood, male family members often shamed him for how he lived out the gendered roles prescribed to him by his family and society. After he was diagnosed with HIV, the isolation he experienced from his family intensified. I believe Lesedi moved to several geographic places, searching for possibilities to live freely as a young gay African man, in order to move away from the oppression of his found community (Friedman, 1989). But his physical move from his found community (i.e., the community where he lived alongside his family and within their culture) to a chosen community (Lindeman Nelson, 1995), did not necessarily erase his stories to live by nested in his found community. In Lesedi's life, I saw the significance of a found community in his stories to live by. Although he physically left his found community to find meaning and to make sense of his identity, he carried the moral space of his found community with him across borders and seas.

The notion of found and chosen communities in the search for narrative coherence was also significant for Rita. Her stories to live by as a Christian woman shaped Rita throughout her life including at the time of her diagnosis, the years that followed her diagnosis, and currently as she continues to live out her life, in the midst of both her found and chosen communities. Telling counterstories (Lindemann Nelson, 1995) to resist the oppression that Rita experienced in her found community was an expression of narrative coherence

(Huber et al., 2004). It was only with time that Rita began to re-negotiate her identity (Lindemann Nelson, 1995) and to come to a place where she no longer felt oppressed by others because of her HIV-positive status.

### **Attending to silences.**

#### ***Silent stories of African immigrants living with HIV.***

I now revisit the untold stories of Lesedi, Rita and Sifa. Stories left out (Bamberg, 2011), whether silent (Bamberg, 2011) or silenced (Neumann, 1997) have significance to understanding narrative coherence or meaning in one's life. Bamberg (2011) raised important questions about stories that people choose, whether consciously or not consciously, to tell or not tell as part of their life narratives. He asks, "what are identities made of and where (or better: when) do identities start? Do identities…encompass whole lives – all experiences ever made? Or do they consist of memories…that are considered relevant enough to feed into one's life narratives?" (Bamberg, 2011, p. 5). These questions remain important in discerning one's stories to live by, or identity. One's stories to live by therefore are shaped by both stories told and stories untold. Stories, whether told or untold live within people, just as people live by such stories (Clandinin, 2013). Silent stories have an important place in one's stories to live by. There may be reasons why stories are untold, silent or silenced. Untold stories speak to experiences, though not spoken of, which shape one's stories to live by. Stories that are articulated or not yet articulated remain alive within people and continue to shape people's lives:

> There are sources beyond the perimeter of the individual that become woven into the fabric of . . . narrative unconscious . . . the culturally rooted aspects of one's history that remains uncharted and that, consequently, have yet to be incorporated into one's [told] story. (Freeman, 2010, p. 96)

Neumann (1997) raised further questions about untold stories: "How can we think of untold stories? How do untold stories manifest themselves, especially in the lives of those who would tell them? What is the significance of untold stories?" (p.93). Neumann (1997) brings important questions to narrative inquirers. Her questions make me wonder about how I can attend to the silent stories of Lesedi, Rita and Sifa. I also wonder about the times that silence filled the narrative inquiry space between myself and each participant and how these silences filled each of us with wonder into the spaces ahead (Neumann, 1997). Neumann (1997) stated:

> People live their stories as much as they tell them in words. They live them in what they do not say. They live them in attending to the words of others rather than their own. They live them in the gaze that comes with inward thought and inward talk while others all around are conversing. They live them in the feelings that come to surround them that they give off in sighs and looks and gestures or simply in the feeling that their presence evokes in others. All of these are forms of telling, though without words, and they are forms of telling that we can begin to read and hear through also without words. (pp. 107-108)

What remains important in attending to the silent stories of Lesedi, Rita and Sifa is to recognize first that each participant has silent stories. Although these stories were untold, it does not mean that a past did not exist for Lesedi, Rita and Sifa. It is within the silent or silenced stories that imagination plays a role in attending to and understanding these stories (Caine & Steeves, 2009):

> Without imagining there is no possibility of becoming . . . Our individual and shared imagination has a life of its own, a life that awakens to a believing-in, and a life that makes us more wakeful to the many stories to live by, while shaping our relationship with others. (pp. 10-11)

Lesedi spoke very little about his relationship with his father. He spoke of having a father and a few memories of his father when he was a child, but he spoke very little of him during the times we spent together. Lesedi's untold stories of his father do not mean that a past does not exist with his father. I attend to these stories by acknowledging that he likely has past experiences with his father, but that he chose to keep these stories silent in our shared inquiry space, whether consciously or subconsciously. I wonder about the silent stories of Lesedi's father and if Lesedi had been silenced *by* his father in the landscape of cultural, familial and social expectations, and how this oppression has shaped Lesedi's life today. Sifa, too had untold stories of her relationship with her siblings. Though she spoke very little about her current relationship with her siblings, I recognize that there is a shared past between Sifa and her siblings that has shaped her stories to live by. Sifa and her siblings were together as children before the Rwandan genocide: they worked together on their family farm, played together, and experienced the loss of their father together.  However, there seemed to be untold stories about how they came together again years after the Rwandan genocide. These stories, though untold remain important to Sifa and her stories to live by. Although these stories remain silent, imagination awakens me to attending to these stories and to the wonder of how these stories might shape Sifa today as an African woman living with HIV in Canada.

Interestingly, Lesedi, Rita and Sifa spoke relatively little about their experiences within the Canadian health care system and use of traditional healers in their home countries, last places of residence in Africa, or in Canada. When our conversations moved towards their experiences of care and support in the Canadian context, Lesedi, Rita and Sifa each composed narratives of positive experiences related to their HIV care within the Alberta health care system. Only Lesedi spoke of several traditional healing experiences he had as an adolescent when his mother attempted to rid him of the “evil spirits” causing his gender identity, as a maturing gay adolescent. As well, Lesedi composed narratives of a traumatizing experience of being tested for and diagnosed with HIV by an Immigration Medical Examination physician in Alberta. Even as I attempted to bring our conversations towards the experience of health care in Alberta, Lesedi, Rita and Sifa would often say “My HIV is okay…” and praise their health care providers for the compassionate care they received. Often Lesedi, Rita and Sifa would depart from conversations about their experience within the Canadian health care system and composed narratives surrounding their life experiences such as familial, social, and settlement narratives of experience. As I reflect on the absence of narratives surrounding experience within the Canadian health care system as well as the use of traditional healers in the management of their HIV illness, I begin to wonder about the silent stories that Lesedi, Rita and Sifa may (or may not) have with respect to this. I wonder about the silence, because of the current literature that documents such experiences (Este et al., 2009a, 2009b; Donnelly et al., 2009; Kaai, Bullock, Burchell & Major, 2012; Lawson et al., 2006; Monteiro, Villela & Soares, 2013). Kaai and colleagues (2012) completed an integrated review examining factors that affect HIV testing and health care services utilization for immigrants and non-immigrants in Canada and the United Kingdom. Factors that are known to shape HIV care and support experiences within the Canadian health care system are many and include: age; legal (immigration) status; ethnicity; socioeconomic status; fear of being labeled; fear of rejection by others; stigma; and inexperience with or little knowledge about the Canadian health care system and how to access health services (Este et al., 2009a, 2009b; Donnelly et al., 2009; Kaai, Bullock, Burchell & Major, 2012; Lawson et al., 2006). In Lesedi’s, Rita’s and Sifa’s narrative accounts, stories of such experiences were almost nonexistent. In this study, each participant’s life narratives were at the forefront of this study, rather than the experience of HIV illness itself. The narratives of experience related to HIV illness was nested within the ‘big’ (Greene, 1995) narratives of each participant’s lives. At this juncture, I awaken to an important consideration. I ask whether I, as a researcher have unintentionally not attended to some of these untold stories, or not attended enough to such stories, or inadvertently played a role in silencing the stories of Lesedi, Rita and Sifa. As I lived alongside Lesedi, Rita and Sifa, there were many times when I inquired into their experience of their HIV care in Canada and/or their countries of origin. I wonder if perhaps there were different ways to attend to such stories of experience. I also wonder if each participant's narrative accounts of health care service utilization would be composed differently in a different time and place, or outside the narrative inquiry space. These questions remain unanswered, but open possibilities for new inquiry.

#### ***Silencing categories of people living with HIV.***

In the previous section and in earlier chapters, I discussed well documented contextual factors that shape people's experiences of HIV illness and health care services utilization (Este et al., 2009a, 2009b; Donnelly et al., 2009; Kaai et al., 2012; Lawson et al., 2006; Montiero, 2013). In Lesedi's, Rita's and Sifa's narrative accounts, some of the factors related to their experience with the Canadian health care system were shared. More importantly, from a narrative inquiry perspective, I learned how each participant's life narratives and search for narrative coherence shaped these experiences more broadly. I did not see Lesedi's, Rita's and Sifa's experiences within the Canadian setting in terms of contextual factors or socially constructed categories alone. As Lesedi, Rita and Sifa composed narratives of their lives, *including* their lives as people living with

HIV, I found that familial, cultural, social and political narratives remained at the forefront of their narratives. It was interesting to understand the place of contextual factors related to each participant's experiences, both of living *and* of living with HIV. That is, such contextual factors were not necessarily at the forefront of composed narratives. Researchers such as Doyal (2009) have examined the interaction between key factors and categories of factors that shape the experience of HIV illness among African migrants in the United Kingdom. Using "intersectionality as methodology", Doyal (2009, p. 174) examined factors such as legal (immigration) status within the host country, gender, culture and the interplay between these factors in the experience of HIV illness. While researchers like Doyal (2009) contribute significant findings in understanding HIV illness as experience through intersectionality methodology, there are limitations to describing experience using this approach alone. First, intersectionality concerns itself with "understanding the effects of race, class and gender on . . . identities, experiences and struggles for empowerment" (Davis, 2008, p. 71).  Placing people in socially constructed categories of race, class, gender and so forth turns away from seeing people "big" (Greene, 1995). Placing people into categories that are used to understand human experience can potentially lead researchers to see people "small" (Greene, 1995, p. 10), from a detached point of view.  In narrative inquiry, people are seen "big . . . in their integrity and particularity . . . in the midst of what is happening [in their lives]" (Greene, 1995, p. 10). Second, intersectionality as methodology (Doyal, 2009), examines commonalities and differences through comparative analysis between groups of people and explores how different socially constructed categories or labels of being interact and shape experience. This too becomes problematic, as I did not set out to compare or contrast people, but rather was looking for resonant threads across and within their experiences (Clandinin, 2013).

Narrative inquiry, as a methodology within the borderlands of other methodologies (Clandinin & Rosiek, 2007) allows for an exploration into the "social, cultural and institutional narratives within which individuals' experiences were constituted, shaped, expressed, and enacted – but in a way that begins and ends that inquiry in the storied lives of the people involved" (Clandinin & Rosiek, 2007, p. 42). Therefore, by examining experience narratively, the focus is not only on the contextual factors that shape people's experiences, but more deeply on the social, cultural and institutional narratives that shape an individual's experience in the world, "an experience that is storied both in the living and the telling and that can be studied by listening, observing, living alongside another, and writing and interpreting texts" (Clandinin & Rosiek, 2007, p. 43). When examining the borderlands of narrative inquiry (Clandinin & Rosiek, 2007) alongside other qualitative methodologies, there are ontological differences when understanding experience. For example, intersectionality as a theoretical framework (Crenshaw, 1989; Bowleg, Teti, Malebranche & Tschann, 2013) and methodology, as described by Doyal (2009) examines human experience through multiple socially constructed categories that people belong to and how such categories interact within social processes and power relations within a society (Bowleg, et al., 2013). Narrative inquiry also examines human experience, but in different ways; people are not categorized into socially constructed labels or identities, and understood through such labels or the interaction of such labels. Rather people are seen in a ‘big’ way (Greene, 1995), looking at how one composes their life narratives, over time, in place and within the sociality (Clandinin, 2013). The notion of placing people in categories (i.e., age, gender, socioeconomic status, legal (immigration) status, and so forth) and understanding human experience through interaction of such contextual factors conflicts with the ontology of narrative inquiry.  Clandinin and Rosiek (2007) cautioned about “the temptation to reify borders, to think of them as real and necessary features of experience” (p. 58) especially within academia. From an ontological standpoint, narrative inquiry does not aim to dichotomize, or categorize human experience, or study the interaction of such categories related to people’s being. Rather, human experience is examined more fluidly, within the three dimensions of the narrative inquiry space (Clandinin & Connolly, 2000). When the borderlands of narrative inquiry, alongside other qualitative methodologies are examined, it becomes important to understand how narrative inquiry, the study of human experience through time, place and social landscapes can “fit with, enlarge, or shift the social and theoretical conversations” (Clandinin & Connolly, 2000, p. 123) around a particular phenomenon of interest.

## Practical Significance

Having a narrative understanding of identity and stories to live by has opened up new possibilities for how to relate with African immigrants living with HIV in Alberta, Canada. From a nursing perspective, there are new possibilities to consider in the care and support of African immigrants living with HIV. I now reflect on how I have been shifted as a nurse and how these shifts shape the ways I relate to people who are experiencing HIV illness, particularly people who have migrated and settled in Alberta from Africa.

### Understanding one's life trajectory as the landscape to one's illness trajectory.

While I do not dispute that the treatment of HIV illness with anti-retroviral medications is critical to the management of the disease, I wonder about the extent that nurses acknowledge the life trajectories of persons living with HIV, specifically people who migrate to Canada from other countries. The biomedical treatment of HIV is undoubtedly important from a public health perspective. However, as Doyal (2009) described, there are limitations to treating HIV only from a biomedical approach:

> [Biomedical and quantitative research] . . . requires the deconstruction of inherently complex variables into separate and unitary items that can be measured and compared. Hence, they cannot be used to make sense of the multiple and interconnected meaning that shape the actions and interactions of all individuals. Nor, can they provide a comprehensive

> understanding of the social, economic and cultural contexts in which personal narratives are created. (p. 176)

For years, I have been involved in HIV work from the perspective of population health promotion and the determinants of health. I worked with colleagues and communities to develop prevention strategies that addressed determinants like housing, poverty, and community development – all factors outside the biomedical management of HIV illness. Looking back at earlier chapters of this dissertation, I discussed several theoretical frameworks that shaped my thinking at the outset of this study. In hindsight, I wonder now if I had been seeing too ‘small’ (Greene, 1995) by having certain expectations about what experiences would matter to the participants of this study. As time evolved, living alongside Lesedi, Rita and Sifa, I began to discover that even these things (i.e., the social determinants of health) were only fragments of the experience of HIV illness, and of their lives. I began to see ‘big’ (Greene, 1995) by living in relation with each participant. I learned that each person’s life trajectory was critical to understanding experience. I think about Dewey’s (1976) notion of experience as continuous, in that experience stretches indefinitely and into the realms of personal, aesthetic and social meaning. The pragmatic ontology of experience (Clandinin & Rosiek, 2007), helped me to focus not only on each participant’s experiences, but also on how the “social, cultural and institutional narratives within which individual’s experiences are constituted, shaped, expressed and enacted” (pp.42-43). This view of experience also awakened me to each participant's experiences in the world, experiences that were "storied both in the living and telling" (Clandinin & Rosiek, 2007, p.43). That is, that one's experiences of childhood, culture, family, gender, as well as one's mundane and sacred stories (Crites, 1971) were important to understanding the experience of HIV illness. Often, I heard Lesedi, Rita and Sifa say "my HIV is ok, but…", which suggested that even though this study was about HIV, HIV illness, and the experience of living with HIV, there were other stories of experience that were important. Or rather, there were other mundane and sacred stories (Crites, 1971) that were equally important to compose alongside the stories of living with HIV, in order to understand Lesedi's, Rita's and Sifa's experience. In this sense, it is critical to honor people's lives in the context of providing support to people living with HIV and treating HIV illness.

### New possibilities for the nurse-client relationship.

Coles (1989) argued that people all too often come with preconceived notions of what matters and what does not matter. As a physician, Coles (1989) discussed his early years as a practicing clinician, reflecting on relationships with his patients and the role of stories in the care of his patients. He stated that people "come with their own lines of inquiry, just as we [health professionals] do" (Coles, 1989, p.14). People hold many stories and how clinicians determine the different ways to give those stories expression plays an important part in supporting people in their illness experience (Coles, 1989). The telling and re-telling of stories opens up possibilities to discover one's stories to live by and to understand the relationship of their illness experience to their life trajectory. Coles' (1989) notion of understanding people in their stories reminds me of when I first began my career as a registered nurse. In the late 1990s, I worked in several acute care settings including an inner city urgent care center and a tertiary care center caring for people with critical cardiac illnesses. Over time, I began to understand that although the biomedical treatment of people's illness and disease was very important to people's physical health, biomedical treatment addressed only a part of people's illness experience. There were times when I felt conflicted as a nurse. For example, I remember when a patient living with diabetes was sent 'home' and instructed to refrigerate his insulin, when 'home' was the streets of the city. Over time I began to realize how little I knew of the people I interacted with in health care institutions. I began to wonder about the lives people had before arriving at the hospital, the lives that people returned to when they were discharged from the acute care setting, and in what ways people's lives would change after hospitalization. The conundrum I experienced within the health care system brought forward questions about who I was and who I was becoming as a nurse. I began to search for new ways to learn about the experience of health and illness, and new ways to view people I met in practice. I began my work in population health promotion in the late 1990s, searching for different ways to work with people in practice settings. I learned about the determinants of health, and the social determinants of health became of particular interest to me. I found myself in a new moral space that seemed more aligned with who I was becoming as a nurse.

Despite this important foundation, through this study, I have found new ways to attend to the possibilities within a nurse-client relationship. This study awakened me to new ways of relating to people, whether they are ill or well. That is, I have discovered the importance of narrative forms of identity, stories to live by, in the life trajectory of people living with illness. Morris (2001) described a postmodern view of illness, a view that disease and illness are intricately linked with culture, experience and emotion. Narratives of illness experiences cannot be separated from life narratives. The two are important to understand the person who is experiencing illness, disease, or wellness. The three participants in the study often composed narratives that their HIV illness was fine, or managed well. I often heard plotlines that the HIV medications were working well for Lesedi, Rita and Sifa. However, what I found particularly interesting was how these plotlines connected to other plotlines in each of their lives. Lesedi often spoke about his challenges in settlement, finding stable housing and employment and the effect of unstable housing and employment on him as an individual. Within these stories of challenges, Lesedi often composed stories of discrimination and stigma which intertwined with his stories to live by as a young gay man. Rita had been living with her HIV illness for nearly 10 years, but I learned that there were many familial and religious narratives that continued to shape her experience and stories to live by as a woman living with HIV in her community. After living alongside

Sifa, I learned about family, cultural and social narratives that have shaped who she is today, as an African woman living with HIV in Canada. I have learned that each participant I met and lived alongside has told and re-told life narratives that have shaped their stories to live by today and will continue to shape their unfolding lives as unique people.

As a registered nurse and nurse researcher, it was important for me to avoid defining Lesedi, Rita and Sifa by their HIV status or illness. As Sabatier (2002) stated, "it is not possible to formulate an adequate understanding of migrants' needs and exposure to HIV without attending to the ways in which the migrants themselves experience and represent their condition" (p. 96). Understanding experience calls for health care providers to attend to specific knowledge of a person's local contexts, their experiences of power and position within family, networks, work, and other social relationships (Sabatier, 2002). Lesedi, Rita and Sifa each composed narrative accounts of their lives, which shape and define who they are and are becoming. It is through these stories told, stories untold, and stories re-told that Lesedi, Rita and Sifa defined themselves. They are not defined by their HIV illness; HIV has only become a fragment of who each person is, or is yet to become (Greene, 1993). My practice as a nurse calls for me to attend to people's lives as always becoming, people living in the midst of their becoming who they are, not yet (Greene, 1993), and attending to people's stories and their silences.

Equally important, I have come to recognize the difference between narrative inquiry as phenomenon in practice and narrative inquiry as a form of practice. Earlier I discussed narrative inquiry as a phenomenon, a way of being and relating with people we encounter in nursing practice. This is very different to other notions of narrative in practice such as narrative therapy, where the goal of using narrative in practice is to find alternative perspectives on life (Walther & Carey, 2009). In other forms of narrative as practice, stories and plotlines of one's life are told to be "understood as opportunities to interrupt usual understandings and habits of thinking and to disrupt familiar problem storylines" (Walther & Carey, 2009, p.8). And while there are similarities to the philosophical foundations of narrative inquiry as phenomenon and methodology (Clandinin & Connolly, 2000), and narrative practice such as narrative therapy (Walther & Carey, 2009), the main difference is that narrative inquirers enter into a relationship with another person, with no intention to disrupt problem storylines or to find alternative perspectives on one's life. Rather, narrative inquirers enter into a relational relationship with another person with the intention to co-compose narratives relating to stories to live by (identity) and to make sense of identity through the search of narrative coherence. However, one of the phenomena I observed in living alongside Lesedi, Rita and Sifa was the transformation that Lesedi and Rita expressed at the end of our research relationship. Central to narrative inquiry as phenomenon and methodology is the researcher-participant relationship. Through this relationship, Lesedi and Rita shared their reflections on how they too have been changed by living together in the narrative inquiry space. Their change was expressed mainly through their search for narrative coherence, making sense of their stories to live by, as well as counterstories, through conversation and relational being within the narrative inquiry space.

### Stories to live by, as a nurse.

Living alongside Lesedi, Rita and Sifa, has (re-)awakened me to my story to live by as a nurse. Living in the shared narrative inquiry space has resulted in new reflections about nursing practice. More specifically, I think more deeply about the role of narratives in nursing practice. Caine (2010) proposed that narratives co-composed with others are “an essential dimension to the practice of nursing, and that our relational narratives are at the heart of nursing” (p. 1304). Engaging with others, the people we live alongside as nurses, is both dialogical and embodied (Gadow, 1999; Caine, 2010), creating possibilities for meaning making through relation and imagination. Sandelowski (1994) suggested that the narrative space between nurse and the nursed can allow for emancipatory narratives, narratives that awaken a person to new possibilities of becoming. No longer should nurse-client encounters be only about collecting nursing histories or managing symptoms. Nor should nurse-client interaction be so focused on illness narratives. The danger to creating “pathography” narratives (Sandelowski, 1994, p. 25) is that we fail to see the client in a big way (Greene, 1995), within a greater context of who they are and the lives they live through stories. It is only when we begin to see ‘big’, the people we live in relation with as nurses that we are able to move towards the emancipatory and healing possibilities of narratives:

> [Narrative can] transform disabling or incomplete, incoherent or overly restrictive narratives to enabling narratives that permit movement towards an integrated sense of self with future possibilities. (Sandelowski, 1994, p.29).

Nurses in practice have the opportunity to engage with people in their respective practice settings and to co-compose narratives of experiences, stories of living, and living stories. Stories, whether told or untold, silent or silenced are central to understanding experience. Nurses are able to co-create spaces with others to compose stories of experience; this enables nurses to attend to such stories at a deeper level. In this way, we are able to view people ‘big’, and not ‘small’ (Greene, 1995) and to live relationally in a deeper way with others.

## Forward Looking Lives

I’ve chosen to end this dissertation with the title “Forward Looking Lives”, rather than “Conclusion”, because I feel that this study has brought me to a point of continuation, rather than ending. I quote Greene (2008) here again, “I am what I am, not yet”. We are still in the midst of becoming (Bamberg, 2011). For Lesedi, Rita and Sifa, their lives will continue to move forward; their lives did not stop at the end of their formal participation in this study. In fact, their participation in this study and their willingness to have me live alongside each of them provided a landscape to tell, re-tell stories that unfolded, shaped and encouraged the expressions of narrative coherence. Although my research relationship has ended with each participant, they will each continue to live in the midst of transition, and of becoming. Participating in this study, alongside the co-participants has opened up new wonders. HIV illness has evolved to become a chronic illness in Canada. People are living longer in the age of effective HIV medications and technologies (Canadian Public Health Association, 2011). I wonder for Lesedi, Rita and Sifa how their lives will continue to shift and unfold within their social, familial, cultural and spiritual landscapes. How will their narrative of past continue to shape their narratives of the future? How will their stories to live by continue to be shaped by these landscapes? How will the people in their lives continue to shape theirs, and how will their lives continue to shape the lives of others? Is there relevance of the study's findings, with respect to stories to live by, found and chosen communities and narrative interlappings to other health and illness experiences such as mental health or chronic diseases? If so, how do these findings shift our practice as registered nurses and how we relate to people we support and care for? All of these new wonders bring possibilities for creating new narrative inquiry spaces to explore other human experiences.

Morris (2001) offers a possibility in finding ways to think *with* stories to contemplate such wonders. That is, to explore the power of narratives to "put us in contact with valuable resources for moral thought and action" (p.56). Too often people think about stories, and not *with* stories (Morris, 2001). We must learn to attend to stories that live within people and to think *with* stories in a way that brings wakefulness and awareness to people we live in relation to:

> Thinking about stories conceives of narrative as an object. Thinker and object of thought are at least theoretically distinct. Thinking *with* stories is a process in which we as thinkers do not so much work on narrative as take the radical step back, almost a return to childhood experience, of allowing narrative to work on us. (Morris, 2001, p. 55)

Further, Clandinin (2013) states that thinking *with* stories means thinking relationally:

> [Narrative inquirers think] about the other's experience [by] thinking of the narratives that shape each person in [their] contexts, in [their] unfolding life, in that moment that comes out of all the other moments and points towards a future. (p.30)

Narratives, told, re-told, and sometimes untold, provide us with a way of knowing and a way of understanding people's lives and identity. Living in the midst of others, being in relation with others is a necessary way of being to understand the continuing unfolding of lives and experiences of people. It is also a necessary way of responding to those around us, and in living our humanity in moral ways.

## Epilogue

At the end of this study, I reflected on several things that continue to unfold for me as a narrative inquirer: the importance of relational ethics, the potential to influence nursing practice, the reciprocity that this study brought between each participant and myself, and the borderland spaces of narrative inquiry.

As the study ended, so too did the formal relationships I had with Lesedi, Rita and Sifa. At the conclusion of our time spent together in the narrative inquiry space, I spoke with Lesedi, Rita and Sifa about how we could evolve together after the life of the study. We each negotiated the ways in which we could stay connected. Since the end of the study, my relationships with Lesedi, Rita and Sifa continue to unfold over time, "within a stream of experiences that generates new relations that then become part of future experiences" (Clandinin & Rosiek, 2007, p. 41). I do not know how our relationships will continue to unfold into the future. However, relational ethics continues to be at the center of my relationship with each person and because of this, I know that I will continue to care for the stories that Lesedi, Rita and Sifa have shared and made public. I am committed to Lesedi, Rita and Sifa as people and to continue to attend to each of them, in their lives and in caring ways.

After writing Chapter 8, I continued to think about the ways that this study may influence nursing in three ways: practice, education and research. I reflected on my past experiences and observations within my nursing practice, in various practice settings and wondered about the place of relational ethics in practice. For example, I wondered about how the nurse-client relationship is often taken for granted in practice or lost in a broader health system that focuses on biometric indicators of successful care. In the current environment of health care in Alberta, there is little focus on understanding people in the midst of their lives and how to attend to people with chronic conditions in the landscapes of their lives. Unfortunately, I continue to observe clients in health care settings who continue to be labelled by conditions, cultures, language barriers and so forth. A major challenge is finding a place, and here I mean a moral place, for nurses to integrate relational ethics into practice. There are few, if any, indicators that measure quality of nurse-client relationships or the relational ethics within the Alberta health care system. I also reflected on the possibilities that may arise in nursing education and research. I think about the possibilities in re-examining how relational ethics is being taught and embodied in nursing education, in examining the (dis)connect in nursing education and practice with respect to relational ethics, and in examining how nurses in practice can attend to the silences that live within people's lives or in the relationships between nurses and clients. Perhaps findings from this study will provide possibilities for changes in practice, or perhaps possibilities for discussion.

I also reflected on the reciprocity that occurred during this study. Reciprocity, occurred in several ways. First, reciprocity lived within the shared narrative inquiry space. This was expressed mainly in the ways we each attended to one another respectfully within the shared narrative inquiry space, a space that embraced relational ethics. Second, reciprocity was expressed in the ways that that each of us contributed to the work of this study. Although I was called "researcher" in this study, I believe that Lesedi, Rita and Sifa each contributed significantly to this work. This work would not have been complete without the willingness and openness to compose the narrative accounts found in this dissertation. Lesedi, Rita and Sifa each carry copies of their narrative accounts. I've learned since the completion of this study that each person has carefully carried their narratives within their personal and social landscapes. Rita shared her narrative accounts with family members. Rita informed me one day that this has shaped new ways of being with one of her children, from whom she had been estranged for some time.

Finally, I continued to reflect on the borderland spaces of narrative inquiry. My purpose of sharing these reflections is to not debate which research methodology or paradigm is the most effective in studying human experience. Rather, my purpose is to highlight how the borderland spaces between different paradigms of inquiry offers unique ways to understand phenomena. For example, from a post-positivist perspective, contextual factors surrounding a particular research problem are acknowledged, but the purpose of the research design is to limit attention to these contextual factors. Clandinin and Rosiek (2007) also described the borderland spaces with critical theorists and other social scientists whose work is grounded in forms of Marxism. Marxist approaches to studying human phenomena are often motivated by the desire to disempower systems of oppression and studies are often conducted as a form of intervention to "change the material conditions that underlie oppressive social conditions" (Clandinin & Rosiek, 2007, p. 49). Borderland spaces with methodologies such as intersectionality methodology or theories related to migration, health and settlement are also useful in understanding human experience. Such methodologies often use categories of people in the analysis of data to understand the influence of contextual factors in health outcomes or the experience of socially constructed categories like gender, poverty, race, and so forth. From a narrative inquiry lens, we move away from placing people in categories to understand experience, and conduct our work without purposeful intention of addressing oppression. Further, we aim to attend to people in the midst of their lives, and through co-composition of narratives, seek an understanding of meaning of people's lived experiences within their personal and social landscapes. Perhaps this is a limitation in not attending to the structural factors that affect people's lives. Narrative inquiry, alongside other philosophical neighbors (Clandinin & Rosiek, 2007), contributes a deeper understanding of phenomena like human experience. For example, the bi-dimensional model of acculturation (Phinney et al., 2006), as described in Chapter 2 was very useful in understanding something as complex as migration and settlement. However, such theories may not capture the spaces between categories of integration, assimilation, separation/segregation, or marginalization (Phinney et al., 2006), nor the complex experiences that shape such categories. Narrative inquiry may provide insights into these categories but more so how these categories live in relation to one another. Also, this study helps one to understand how complex the concept of cultural safety is, as it requires us to remain wakeful to our vulnerabilities as co-researchers.

With these final thoughts and reflections, I hope that these and the findings of this study continue to open possibilities for further inquiry, or at the very least be a departure point for new discussions about the ways we can continue to live relationally with one another.

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# Appendix: Participant Information, Consent Form and Ethics Approval

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

**Title of Study:**
A Narrative Inquiry into the experiences of Sub Saharan African immigrants in Alberta living with HIV

Principle Investigator: Dr. Judy E. Mill

Sub-Investigator: Añiela M. dela Cruz, PhD Student (researcher)

**Purpose of Study**
You are being asked to participate in a study that will explore and understand *the experiences of Sub Saharan African immigrants living with HIV in Alberta.* You will meet with the researcher to share your life stories about living with HIV in Alberta.

**What will you do?**
Participating in this study will involve:

a) 5-6 of visits with the researcher at a site you choose to share your experiences and stories. The site can be at a clinic, an organization, or anywhere you feel safe and comfortable.

b) During these visits you will have an opportunity to share your experiences of living with HIV in Alberta. Each visit can be between 1-2 hours.

c) Your stories will be recorded.

**Will it help you?**
By participating in the study, you will be able to share your personal stories of living with HIV in Alberta as an immigrant. Many people feel sharing stories allows them to have a voice in sharing stories or experiences.

**Will anything hurt?**
There are no physical harms if you participate in this study. But sometimes, sharing personal experiences and stories can be upsetting. Sharing stories can

bring up your negative experiences in the past or bring up sad memories. You might become upset and sad during your visits, but support will be provided during these times.

**Who will know that you participated in this study?**
Personal information and experiences shared during the study will be kept confidential. Only you and the research investigators will know you participated in this study. Any information collected about you will not identify you by name, and only by a file number. Any report published about this study will not identify you as a participant to this study. If you want to be identified as a participant in the study, please inform the research investigators. It is up to you to make this decision and you can change your mind any time during the study.

**Can you quit anytime?**
You are free to leave the study at any time you want to.

**Will it cost you anything to participate?**
You will be reimbursed for each visit, to cover transportation expenses such as public transit, taxi or parking. As well, you will be provided an honorarium to compensate you for your time in the study. An honorarium of $50 will be provided for each interview completed, for a maximum of $300. If you decide to leave the study before you finish your interviews, you will still be given an honorarium for each interview completed.

**Your signature**
We would like you to sign this form to show that you agree to take part in the study.

**Do you have more questions?**
You can call Añiela dela Cruz at 403-608-8046 at any time to ask any questions about this study.

**Contact Names and Telephone Numbers:**
If you have concerns about your rights as a study participant, you may contact the Research Ethics Office at (780)492-2615. This office has no affiliation with the study investigators.

Please contact either of the individuals at any time if you have any questions or concerns:

1. Dr. Judy Mill, Principle Investigator

(780) 492-7556

2. Añiela dela Cruz, Co-Investigator, PhD Student
(403) 608-8046 - Confidential telephone line, voice message and text messaging.

**Part 1 (to be completed by the Co- Investigator):**

Title of Project: Exploring and understanding the lived experiences of Sub Saharan African immigrants in Alberta who are living with HIV

Principal Investigator(s): Dr. Judy Mill Phone Number(s):780-492-7556

Co-Investigator(s):Añiela dela Cruz Phone Number(s): 403-608-8046

______________________________________________________________________

**Part 2 (to be completed by the research subject):**

| | Yes | No |
|---|---|---|
| Do you understand that you have been asked to be in a research study? | ☐ | ☐ |
| Have you read and received a copy of the attached Information Sheet? | ☐ | ☐ |
| Do you understand the benefits and risks involved in taking part in this research study? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? | ☐ | ☐ |
| Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care? | ☐ | ☐ |
| Has the issue of confidentiality been explained to you? | ☐ | ☐ |
| Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name ___________________ | ☐ | ☐ |

Who explained this study to you?

_________________________________________________________

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Subject

__________________________________________________________

(Printed Name)

________________________________________________________________

Date:________________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ________________________________ Date __________

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT**

## Approval

Date: March 23, 2012

Study ID: Pro00021018
Principal Investigator: Judith Mill
Study Title: A Narrative Inquiry into the Experiences of Sub-Saharan African Immigrants in Alberta Living with HIV
Approval Expiry Date: March 22, 2013
Sponsor/Funding Agency: College and Association of Registered Nurses of Alberta

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application, including revisions received March 19, 2012, has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041.

Enquiries regarding Covenant Health should be directed to (780) 735-2274.

Sincerely,
Dr. Jana Rieger
Chair, Health Research Ethics Board - Health Panel

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

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