BECAUSE SHE CARES: RE-MEMBERING, RE-FINDING, AND POETICALLY RETELLING NARRATIVES OF HIV CARING WORK WITH, FOR AND BY AFRICAN WOMEN LIVING WITH HIV

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Submitted to the School of Graduate Studies at McMaster University in Partial Fulfilment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

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BECAUSE SHE CARES: POETIC RETELLINGS OF HIV CARING WORK
Descriptive Note

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TITLE: Because she cares: Re-membering, re-finding, and poetically retelling narratives of HIV caring work with, for and by African women living with HIV

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Lay Abstract

Guided by decolonizing, anti-colonial, and transnational feminist thoughts, the Because She Cares study aims to understand the experiences of African women living with HIV who are employed in the HIV sector in Ontario, Canada. Study aims include better understanding HIV-related work as agential, cultural and social practices of caring work and deciphering its local and transnational interconnections.

Ten African women with employment histories in Canadian AIDS service and allied organizations (AASOs) participated as the Narrators. Using performance narrative methods based on oral traditions, I gathered, interpret and shared their stories of HIV caring work and “retold” narratives as poems. Study findings illuminate the multiple self, communal and social modes of caring that emerged in women’s HIV-related work, the shifting responsibilization of African women living with HIV as carers, the intersecting systems of oppression African woman navigate in Canadian work spaces and strategies of care-full work that translocates “back home”.
Abstract

Research on employment in Canadian AIDS service and allied organizations (AASOs) should recognize the unique experiences of immigrant women workers of African descent given their transnational HIV histories, working roles, relationship and responsibilities, interconnected identities and senses of belonging, and intersecting systems of oppressions they navigate within their working lives. Guided by decolonizing, anti-colonial, and transnational feminist thoughts, the Because She Cares study aims to understand the experiences of African women living with HIV who are employed in the HIV sector in the province of Ontario, Canada. Using performance narrative methodologies, this inquiry explored HIV-related work as agential, cultural and social practices of caring work; and deciphered the local and transnational interconnections to African women's sensemaking of their work as HIV caring work.

Ten African women with employment histories in Canadian AASOs participated as the Narrators. Using performance narrative methods based on oral traditions, I gathered, interpret and shared their stories of HIV caring work. In collaboration with the Narrators, I poetically “retold” interview narratives to embody the emotive resonance of the original telling and evoke the theoretical and political relevance of the sharing. Study findings illuminate the multiple self, communal and social modes of caring that emerged in women’s HIV-related work, the shifting responsibilization of African women living with HIV as carers, the intersecting systems of oppression African woman navigate in Canadian work spaces and strategies of care-full work that translocates “back home”.

This study documents work experiences of African women whose HIV-related engagement is notable yet, typically overlooked in Canadian research on HIV-related employment and civic engagement. Decolonizing, anti-colonial, and transnational feminist thinking allowed me to use
culturally responsive methodologies that highlight how HIV caring work becomes processes of identity and belonging, and its corresponding rights and responsibilities, within and across local and transnational contexts.
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<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AASO</td>
<td>AIDS Service and Allied Organizations</td>
</tr>
<tr>
<td>ACB</td>
<td>African, Caribbean and Black Canadian Communities</td>
</tr>
<tr>
<td>ACCHO</td>
<td>African And Caribbean Council On HIV/AIDS in Ontario</td>
</tr>
<tr>
<td>ACT UP</td>
<td>AIDS Coalition to Unleash Power</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS Service Organization</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-Based Organization</td>
</tr>
<tr>
<td>CBR</td>
<td>Community-Based Research</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People Living with HIV</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>ICW</td>
<td>International Community of Women Living with HIV</td>
</tr>
<tr>
<td>LGBTQ2</td>
<td>Lesbian, Gay, Bisexual, Transgender, Queer and Two-Spirited.</td>
</tr>
<tr>
<td>MEPA</td>
<td>Meaningful Engagement of People Living with HIV</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>OACHA</td>
<td>Ontario Advisory Committee on HIV/AIDS</td>
</tr>
<tr>
<td>OAN</td>
<td>Ontario AIDS Network</td>
</tr>
<tr>
<td>OHTN</td>
<td>Ontario HIV Treatment Network</td>
</tr>
<tr>
<td>PHA/PLHIV</td>
<td>Person Living With HIV</td>
</tr>
<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organization</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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</table>
Chapter 1: Introduction

A few years ago, I attended the annual general meeting of an AIDS service organization (ASO)\(^1\) of which I am a member. During this meeting, one of my colleagues\(^2\), a support worker at an ASO got up to speak about her work experiences as an African woman living with HIV. As she talked about her journey from continental Africa to North America, from being a service user to becoming a ASO worker, one sentence in her story stood out to me:

“I work at this ASO because I care about my community.”

Because she cares. That one sentence elicited many questions for me as I tried to understand what HIV-related work as caring work could mean for my colleague. What does it mean for her to work at an ASO because she cares? Who are her communities, and its members for whom she cares? What does it mean for her to engage in HIV-related work, as a person living with HIV and as an immigrant\(^3\) woman living in Canada? How did her temporal and geographical journeys bring her to HIV-related work? How did HIV-related work become works of caring?\(^2\)

As I reflected on these questions, I started to realize that underlying them were assumptions about HIV-related engagement, caring work, and employment that were grounded in common narratives, some would say dominant narratives\(^4\), of social justice mobilization, work...

Notes:

1 AIDS service organizations (ASOs) are usually defined as community-based organizations that provide care and support to people with HIV, as well as provide services related to HIV prevention, testing, and education to the broader community.

2 To represent the many African women who have worked in the HIV-response, I created a composite character that emerged from various stories of African women living with HIV who shared their experiences working in the HIV-response at community forums. The use of composite characterization as a representational device is inspired by the work of Derrick Bell (1989, 1993).

3 In lieu of using the terms newcomer, migrant and refugee, I use immigrant as a general term for a person who has migrated to Canada from another nation-state.

4 Throughout this thesis, I use the term “dominant narrative” to indicate cultural narratives of a phenomenon that become universalized, meaning other understandings of said practice are discounted or silenced. Commonly, these dominant narratives are derivative of the worldviews of the socially privileged such that their ways of understanding the world becomes the status quo and their cultural values, perceptions, and beliefs become adopted and culturally promoted as the predominant or primary way of understanding the world.
participation and civic engagement. Narratives of work that also articulated societal values and corresponding roles and responsibilities. But were these assumptions grounded in her sensemaking of caring work as an African woman living with HIV? What did working because she cares mean for her? My experiences listening and learning from the narratives of people living with HIV, immigrant women and peoples of African descent have led me to ponder HIV-related work as caring work and what such caring work might mean for African women living with HIV.

**Purpose of the Study**

The purpose of my doctoral research — the Because She Cares study — is to better understand how African women living with HIV who have been employed in AIDS service and allied organizations (AASOs) in Ontario, Canada makes sense of their work as caring work. I thought it timely to explore this topic given the transition of HIV from a terminal to episodic illness, the increasing participation of people living with HIV as employees within the HIV sector, and the prominent participation of African women living with HIV within local and transnational civil society responses to HIV. This inquiry aims to:

1) Document the work narratives of African women living with HIV using culturally responsive, arts-based approaches to story-telling and sharing;

2) Interpret the ways in which African women living with HIV made sense of their HIV response activities as cultural and social practices of work and care as well as the relationship between them; and

3) Decipher the local and transnational interconnections between social positioning, identity, and belonging to African women’s sensemaking of HIV-related work as caring work.
Using decolonizing, anti-colonial and transnational feminist perspectives, this study illuminates the ways in which HIV-related work becomes individual and social practices of belonging and its corresponding rights and responsibilities within and across local and transnational contexts. It uses performance narrative methods to critically decipher the agential and cultural narrative of HIV, work and caring labour that emerges from women’s narratives and to poetically retell women’s stories in a manner that embodies the emotive resonance of the original narrative telling and evokes the theoretical and political relevance of the sharing.

Significance of the Study

This study aims to document the work narratives of African women whose engagement in HIV response activities worldwide is notable yet, typically overlooked in Canadian research on HIV-related employment and civic engagement. Employing decolonizing approaches to knowledge generation with, for and by peoples of African descent, we — the women I interviewed and myself — co-constructed culturally responsive approaches to knowledge generation, or what Bagele Chilisa (2012) defined as research processes that respond to social, political and historical context of knowledge generation for people from colonized cultures. Part of that response is incorporating local knowledge systems of the peoples for which the research is intended. Using anti-colonial and transnational feminist perspectives allowed me to explore the local and transnational contexts of work participation and caring labour, its geographies of power and interconnected colonial legacies articulated in contemporary contexts. These critical theories allowed me to illuminate the experiences of HIV-related work as caring work as it intersects with HIV, gender, race, nation and other social positionings, and highlight the ways in which HIV-related work becomes individual and social practices of belonging, its corresponding rights and responsibilities, with and across local and transnational contexts. I endeavoured to
produce research that could have some utility for African, Caribbean and Black communities within which I work with and for, and to centre my inquiry on a group of women who inspire my continued work in HIV responses. What started out as a personal inquiry — why and how do African women care through their work — has also become a responsibility — as an ally and member of ACB HIV activist communities — to share the stories of African women living with HIV who have and continue to work in response to HIV, in Canada and in their homelands, locally and transnationally, because they care.

**Social Positioning**

My social positioning as a second-generation Canadian of Afro-Caribbean descent guided my research including its topical focus, epistemological framework, methodological choices, and writing style. Additionally, I desired to conduct this inquiry as an allied volunteer, service provider, and researcher engaged in HIV responses in Canada. I believed my identification as an ally and senses of belonging as a person of African descent guided my puzzling of cultural narratives of civic engagement, HIV-related mobilization, and caring work — understandings of “engagement”, “responsibility”, and “community” for instance — that were articulated within African women’s narratives of HIV-related work. What primarily inspired me to do this study — its topic, theoretical framework, methodology, and political stances — were my working relationships with African women living with HIV as co-researchers, work colleagues, mentors, advocates, volunteers and friends. I conducted this research because I care. I learned a great deal from listening to the working stories of African women living with HIV; now it is time for others to learn from their experiential wisdom as well.

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5 “Ally” is a term commonly used in HIV responses to identify people who are HIV-negative and actively engaged in response activities.
Definition of Terms

**Work-related terminology.** I define *HIV-related work* as voluntary or paid work that provides care or support to people living with HIV or offers services related to HIV prevention, education, treatment, and support to the broader community. I use *HIV-related employment* when explicitly speaking about HIV-related work as paid work or labour market engagement, or *AASO employment* when specifically referring to someone’s employment in an AIDS service or allied organization. I refer to the *HIV sector* when speaking of organizations that are involved in such work such as AIDS service or allied agencies that are mandated to provide HIV-related services (e.g., hospitals, community health centers, immigration service organizations, ethnocultural organizations etc.), or organizations that perform work activities integral to HIV responses (e.g., research organizations, health and social service academic institutions). When referring to AIDS service and allied organizations that comprise the HIV sector, I use the acronym *AASO*.

My use of the term *caring work* initially drew upon the caring labour literature; yet my interpretations of *HIV caring work* are centered on how the women I interviewed made sense of their HIV-related work as caring work, particularly if they spoke about their work in a manner that demonstrated affective or emotional connections (e.g., love for one’s employment), or senses of duty or responsibility (e.g., employment for material remittance to homeland families). Though I use “caring labour” when referring specifically to this body of literature, I also use the term *labour* to emphasize its arduous process such as work that could be potentially harmful for the practitioner (i.e., HIV-related work that is emotionally demanding or financially precarious).

**HIV terminology.** My use of HIV-related terms primarily adopts UNAIDS terminology (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2015). As HIV has evolved into a
chronic health condition and its response activities have shifted towards halting the development of acquired immunodeficiency syndrome (AIDS), the use of the AIDS acronym has become less frequent. As such, I use HIV or HIV-related as a classifying term (e.g., HIV-related work) or to identify people who have been diagnosed as HIV-positive (people living with HIV, African women living with HIV). I avoid using HIV/AIDS unless it has been stated by a person I interviewed or has been adopted within naming conventions. I only use “AIDS” when specifically referring to acquired immunodeficiency syndrome. Yet, there is an exception: AIDS service organization (ASO) continues to be used to denote organizations whose mandate directly addresses HIV or AIDS, so I adopted this acronym.

**Civic engagement terminology.** My understanding of HIV-related work recognizes its roots in grassroots mobilization, where people living with or affected by HIV generated the initial mobilization from which response activities are founded. This study acknowledges the role active participation of people living with HIV have had in developing HIV response activities and founding AASOs worldwide. For instance, this study frequently uses the acronyms GIPA and MEPA to recognize the principles of greater involvement of people living with HIV (GIPA) and meaningful engagement of people living with HIV (MEPA) in all aspects of HIV responses (UNAIDS, 2007; Ontario HIV Treatment Network (OHTN) & Ontario AIDS Network (OAN), 2014). However, I also recognize that these terms have been contested amongst people living with HIV themselves. Various reiterations of GIPA and MEPA (i.e., Greater Involvement of Women Living with HIV/AIDS (GIWA), Meaningful Involvement of People Living with HIV (MIPA), Meaningful Involvement of Women and Girls Living with HIV/AIDS (MIWA), and Meaningful Engagement and Inclusion of People Living with HIV/AIDS (MEIPA) for example) have been devised to denote the diverse representation of people living with HIV and
the importance of recognizing their civic engagement, some of which feature in narratives of work (e.g., MIPA in lieu of MEPA). While I primarily use GIPA and MEPA within this thesis — GIPA as it is the principle ratified internationally, MEPA as the prominent stance of people living with HIV at the time of this writing, GIPA/MEPA as the acronym for these principles — I also acknowledge these other variations. These variations suggest that GIPA though endorsed by the United Nations and its member states is not inclusive of all perspectives of involvement; as such, this thesis explores GIPA and MEPA as cultural narratives of social participation.

I primarily use the definition of civil society used by the United Nations: the third sector of society that works alongside government and business to fulfil societal needs (United Nations, u.d.). My use of the term includes formal and informal social collectives (i.e., non-profit, voluntary, grassroots organizations, and informal networks) and its members who become civically engaged for the betterment of society (Rice & Prince, 2013). However, in using this term, I recognize its Euro-Western origins; moreover, its usage can evoke liberal understandings of non-governmental collectives such as civil society as formalized or ordered "civility" that works alongside public and private sectors to preserve the status quo (Comaroff & Comaroff, 1999). Like John and Jean Comaroff (1999), I argue for a conceptualization of civil society that is critical of its Euro-Western liberal origins, and its moralized interpretation of participatory governance and social development. Similar to David Lewis (2002) I strive to recognize the multiple local applicability of civil society, and how it is taken up amongst African peoples engaged in varied acts of civic participation — political action, founding AASOs, policy

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6 I use the term “Euro-Western” to denote European and Western imperialist (i.e., Spain, Portugal, France, the Kingdom of England/Great Britain, and the Netherlands) and settler states (i.e., Canada, Australia, and the United States). I distinguish Euro-Western settler states such as Canada, Australia, and the United States from those in the Southern Americas because their dominant social order privileges European and Western imperialist worldviews.
advisement, research, caregiving — to assure the social betterment of people living with and affected by HIV.

Because non-profit organizations exist as local, regional, or international organizations, I define them differently within the Because She Cares study. I primary use community-based organizations or CBOs to denote local non-profit organizations such as local AASOs; I use non-governmental organization or NGOs when speaking about supranational or international non-profit organizations that engage in HIV response activities or employ people living with HIV.

**Place/Space terminology.** The terminology I use to define place and space recognizes spatial terminology as socially constructed, which can represent and be representative of geographies, identities, collectivities, histories, and senses of belonging (K. Brickell & Datta, 2011). For instance, I use the terms African and Canadian to not only denote geographic locales, but ways in which African women living with HIV are located and locate themselves and their work practices. Many of the women I interviewed used the term “African” to name the regional area of their homelands but also used it to identify themselves and some of the collectivities to which they belong. They also used “African” to denote cultural precepts and practices. The women I interviewed occasionally used the term “ACB” as a self- or collective identifier; ACB, is an acronym commonly used in Ontario HIV responses to refer to African, Caribbean and Black Canadian communities who are impacted by HIV (ACCHO, 2013). I used the terms “African descendant” and “African descent” to refer to people who identify as descendants of continental Africa (e.g., Black Canadian, African-American, Afro-Brazilian) as adopted by the United Nations (United Nations Human Rights Office of the High Commissioner, 2015).

As racial and national identifications became relevant to how African women living with HIV positioned themselves and were positioned within their work, I strived to use the
terminology that the women used themselves (e.g., “Black”, “black African”, “African”, “ACB”), but in my interpretations used *African* and *person/peoples of African descent* to denote regional and racial identifications respectively. While many scholars debate the use of terminology that essentializes racial identity, in the context of this study, shared racial identifications with the women I interviewed seemed to play a prominent role. While the women I interviewed racially identified themselves in different ways (i.e., “Black” as a racial identifier varied across social contexts; “African” and its derivatives interchanged between ethnocultural and racial identifications) what seemed to underlie this shared identification were historical and current experiences of colonial oppression perpetuated through Black racism and racialization.

The women I interviewed would also use “home” to denote the geographical location of their land of birth, their ancestral land, or the place(s) for which they have developed senses of belonging. I use the term *homeland* to denote the geographical location they identified as their country of origin, and *back home* as they used it to denote places or spaces in which they had established a sense of history, belonging or communality.

**Thesis Organization**

This thesis is organized as follows:

In Chapter 2, I conduct a critical review of what is currently known in the fields of HIV work engagement and caring labour as relevant to this thesis with an emphasis on the literature on civic, social, political and labour market engagement of African women living with HIV in response activities within sub-Saharan Africa and North America. I also incorporate the conceptual and theoretical literature on caring labour and citizenship to make sense of HIV-related work as process and practices of self, communal and social caring.
In Chapter 3, I discuss the ways of knowing that guide the Because She Cares study. I present the decolonizing, anti-colonial and transnational feminist perspectives that shape the study’s epistemological framework. In this chapter, I emphasize the personal and political impetus to decolonize doctoral knowledge generation with, for and by peoples of African descent, the anti-colonial stances that guide this decolonizing knowing, and the transnational feminist theories — translocality, and translocal intersectionality specifically — that aided interpretations. I also discuss decolonizing knowledge generation as translocal consciousness for academics of African descent who ways of knowing are shaped by their multiple worldviews within and across transnational spaces and places.

In Chapter 4, I introduce performance narrative inquiry, the knowing practices used for the Because She Cares study. In this chapter, I take you along my critical reflexive journey, where I reflect upon (or what I call ponder and grapple) doctoral knowledge generation as decolonizing, anti-colonial and transnational feminist praxis, and how my approach to performance narrative inquiry strives to create greater space for participants as co-knowers in knowledge generation. Notably, I explain my critical, iterative approach to knowledge generation, and how I “found” culturally responsive approaches to performance narrative methods through my engagement with African women living with HIV.

In Chapter 5, I grapple with the ethical and moral implications of conducting culturally responsive knowledge generation with, for and by peoples of African descent. I explore the tensions of research “validity” and “rigour” from a decolonizing, anticolonial, and transnational feminist stance, and offer approaches to research validation that are centered on relational axiology: research relationships, its accountabilities and broader social relations. I also reflect upon the moral implications of conducting decolonizing, anticolonial, transnational feminist
knowledge generation such as the potential moral tensions I encountered as a Ph.D. scholar of African descent conducting doctoral research with and for African women living with HIV, and as an HIV researcher who is engaged and embedded in the community spaces for which this research is understanding and critiquing.

In Chapter 6, I share what I learned from the women I interviewed, whom I call the Narrators. Notably, I convey how the Narrators’ sensemaking of HIV-related work with and across local and transnational contexts conveyed intersecting cultural and agential narratives of how work should and could be caring work for African women living with HIV, what I call HIV caring work. To illustrate HIV caring work for African women living with HIV who work in Canadian AASOs, I share the stories of five Narrators who teach us the ways in which HIV caring work can be vocal work, a “calling”, (un)supportive work, “successful” work and emotional work.

In Chapter 7, the concluding chapter, I revisit the question that originally led me to conduct this research: what does it mean for African women living with HIV to work in AASOs because they care? In bearing witness to the “teachings” of the Narrators, I contemplate the ways in which HIV caring work as civic, social, political, and labour market engagement can become reciprocated care, the potential uncaring nature of HIV-related work when the environment within which African women living with HIV work is unsupportive or oppressive, and the ways in which the Narrators re-membered, re-found and translocated ways of working that cared for them. I discuss the implications of the Because She Cares study and its contributions to the theoretical, methodological and topical fields, and its contributions to Social Work and HIV research. I also reflect upon the study’s limitations and suggest future work that could result from study findings.
Chapter 2: What the Field Knows So Far (Literature Review)

To situate the Because She Cares study, I referred to the literature on HIV work engagement and caring labour to better understanding how HIV-related work can be understood as caring work across local and transnational contexts. I begin this chapter with the conceptual literature on caring labour to foreground my understanding of HIV-related work as caring work. Next, I organized the literature around four salient themes: HIV-related work as caring through peer work, caring through professional work, caring work as women’s work, and caring work as citizenship work. I end this chapter by identifying theoretical, methodological and knowledge gaps in the literature that the Because She Cares study aims to address.

For people living with HIV, caring through peer work could shape self- and social constructions of HIV seropositivity; notably, the literature highlighted the civic participation of African women in local responses and its transnational implications. As HIV responses have progressed, so too has caring through peer work, with many voluntary working roles evolving into employment opportunities for people living with HIV. The literature on HIV-related work as caring through professional work emphasized the opportunities and tensions of realizing greater involvement and meaningful engagement through one’s employment. While caring work can be life affirming for African women living with HIV, it can also be complicated by gendered and nationalized roles of caregiving and work participation. The literature explored caring work as women’s work: caring work through the purview of HIV, gender identity and interconnected gender relations and performatives. Lastly, caring work can become practices of realizing one’s rights and responsibilities as a member of a communal or state body. The literature on caring work as citizenship work explored HIV-related work as practices of civic belonging and social participation. Surveying the literature highlighted how the HIV-related work of African women
living with HIV can be understood as HIV caring work and how common understandings of HIV, work, and caring labour could be articulated, troubled and reframed through African women’s experiences of working in AASOs.

Conceptualizing Caring Labour

_Caring labour_ commonly refers to the work activities ascribed to reproductive labour, or work that aids in the reproduction, sustenance, and care of a society (Folbre, 1995). This idea of caring labour includes work conducted within public and private spheres, and with or without material remuneration such as domestic care, family care, health care, social service work, and education (Hochschild, 2003). Feminist theorists debated about the reification of caring labour as women’s work. Within these debates, theorists questioned the devaluation of caring labour due to its roots as unpaid work, its perceived innate skills, the alleged predisposition of women to caring tasks, and the gendered social divisions of work (Neysmith & Reitsma-Street, 2005). These debates interrogated the feminization of caring labour, its essentialized attribution to female gender identities, roles and responsibilities, and its links to the social devaluation of many caring-related occupations and their segregation within secondary labour markets (Vosko & Clark, 2009).

While feminist debates on caring labour challenged notions of caring work as women’s work, more recent literature on caring work as employment considered the _ethnoracialization of caring work_. While globally women are primarily engaged in activities of care, scholars emphasized that experiences of women’s employed in caring labour in Western contexts is not uniform: instead, the who of caregiving — often racialized immigrant women — represented systems of social privilege and marginalization (Neysmith, 2000). Furthermore, some feminist scholars underscored the _transnational nature of ethnoracialized women’s caring work_ that was shaped by
different factors: migration patterns from Southern to Northern countries\(^7\), women’s increased participation in the labour force coupled with the retreat of social welfare worldwide, the global transfer of caring work activities from formal institutional settings into community-based and informal care settings, and immigrant women’s caring activities occurring across nation-states (Zimmerman, Litt, & Bose, 2006). The literature illustrated how caring labour and the commodification of care reaffirmed social hierarchies locally and globally that interconnect with gender, class, race, nativity, and immigration status (Neysmith, 2000).

The gendered, ethnoracialized, and nationalized aspects of caring work demands understandings of African women’s work that consider intersecting systems of privilege and oppression; globalization and corresponding migration patterns; the varied locales within which African women engage in caring work; and corresponding gendered roles, responsibilities and performatives (M. Wong, 2006). Though there are some tensions with defining caring labour as reproductive work as it reaffirms gender divisions of labour processes, conceptual sensemaking of caring work should also contemplate its social reproductive qualities: the reproduction of citizens, labour production processes, social identities and ideologies (Kofman, 2012).

**Understanding HIV-Related Work as Caring Work**

Many of the working roles defined as HIV-related work — health, community service, social service, and community-based research (CBR) — reside within the spheres of caring work. What makes HIV-related work a unique form of caring work is the potential simultaneity of caring: the

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\(^7\) Within this paper *Southern* or *Global South* refers to countries within Africa, the Caribbean, Latin America, Asia, and Oceania (except for Australia). *Northern, Western, or Global North* refers to Canada, United States, Australia, and countries in Europe. While these terms have been used to denote geopolitical locations, or socio-economic divides, the particular usage in this paper denotes political and ideological divides, particularly those informed by colonial histories: *Global South* indicates former European colonies, and *Global North* indicates former European imperialist rulers or settler countries (e.g., Canada, United States, and Australia).
caregiver, a person living with HIV, can also be the care recipient. Additionally, the mobilization of people living with HIV has galvanized their active participation in all aspects of HIV programming, planning, research, policy, and related work (UNAIDS, 1999).

Though HIV-related work as voluntary or paid work in human and social services can be considered a formal practice of caring work, it can also be informal practices as well, or the work that people do on behalf of local HIV responses to demonstrate their affinity with or affection for other people living with HIV, or to reciprocate the care once received as a client. For some African women living with HIV, engagement in HIV-related work as employees or volunteers can become self-care: a way to (re)enter the Canadian labour market and achieve material subsistence, an opportunity to connect with others living with HIV, or a route to service information and programming available to people living with HIV (Bartos & McDonald, 2000). Self-care may also involve healthwork: the work activities that people living with HIV engage in to maintain their health and quality of life (Mykhalovskiy, 2008).

Caring work for African women living with HIV can also become caring for one’s community: a collective means of supporting individuals who are affected by or infected with HIV. Moreover, working alongside other people living with or impacted by HIV can create community through HIV caring work. People who work in HIV responses, frequently use the word community to designate with and for whom they conduct their work. HIV communities can evolve from shared experiences of HIV seropositivity, and reconstructed self- and social identities derivative of its conscious-raising, life-transforming aspects (Bartos & McDonald, 2000; Robins, 2006). The term community also harkens back to the origins of HIV mobilization as civil society responses, where collectives of people who shared a common interest to realize their rights of care spearheaded the development of HIV prevention, education, treatment, care, and cure (i.e., HIV
response) activities (Lee et al., 2016). Community can also represent a neighbourhood, land of birth, or lands of settlement; home community could be a geographic locale, a memory of one’s ancestral place or nation of birth, or a collective with whom one engenders a sense of belonging. Consequently, the communities for and with which African women care can have multiple meanings: people with similar lived experience, shared cultural affiliations, or similar worldview.

The literature I reviewed on HIV, work and caring labour emphasized the ways that HIV-related work can be understood as caring work for African women living with HIV. This literature illustrated how HIV-related work as caring work could articulate identities, social collectivities, senses of belonging, social values, performatives and power relations across local and transnational social fields.

Caring through Peer Work

HIV activism is notable for its practices of identity and identification. As an “epidemic of signification” (Treichler, 1987, p. 263), an “embodied epidemic” (Jungar & Oinas, 2013, p. 178), and a “creation of community out of a ‘tragedy’” (M. Alvarez & Candelario, 2001, p. 254), HIV and its activism embodies the marginalization and stigmatization attributed to the condition as well as communal action and identity consciousness accredited to HIV movements. In Canada as well other Western contexts, HIV responses adopted the term peer to represent HIV-related identities and collectivities (Poindexter, 2006). As a term of identification, peer refers to people living with HIV who are actively involved in HIV response activities. As a term of collectivity, peer signifies communal belonging that has been forged through shared experiences of living with HIV.

For African women living with HIV who may also identify to gender, racial, national, regional or other affiliations, their understanding of peerhood may transcend HIV and
encompass other identities they embrace or embody as women, homeland community members, Africans, and peoples of African descent. Like HIV, these other social identities may articulate and resist marginalized social positioning and experiences of gendered, racialized, nationalized, regionalized and other intersecting systems of oppression. It is the ideals of collectivity, identity, and belonging that shape understandings of HIV-related work as peer work, which I define as the processes and practices in which African women living with HIV actively engage amongst people with whom they identify and commune.

The literature highlighted the possibility and tensions of HIV-related work as caring through peer work: activism as self, communal and social care; the formalization of peer work through mandated principles of civic participation; dominant and divergent understandings of peerhood in HIV contexts; and hierarchies of peerhood as constitutions of societal positionings and its power relations.

**Peer work as self- and collective care.** In the early days of HIV movements, self- and social care activities amongst people living with HIV became seminal in forging social networks amongst people with shared experiences of HIV, raising awareness around HIV and interconnecting systems of oppression, and realizing one’s rights to care (Robins, 2006; Roy, 1995; Stockdill, 2001). HIV collectivity has a particular ideology shaped by identification with one’s seropositive status, conscious-raising around one’s rights as a person living with HIV, and collective belonging centered around common experiences of seropositivity.

In Michael Bartos and Karalyn McDonald’s (2000) seminal work, they explored how HIV care activities can forge HIV collectivity and consciousness. They highlighted the ways that self- and collective care activities can become “modes of subjectification” (Bartos & McDonald, 2000, p. 300) and that the work of caring developed individual selfhoods as well as peerhoods,
or particular modes of HIV subjectivity. For some people, HIV can become central to one’s self-identity, and peerhood and can germinate a consciousness of living with, and identifying with HIV (Bartos & McDonald, 2000).

While HIV self and collective identifications have been integral to the conscious raising that emerges from HIV mobilization, it underlies modes of HIV conscious-raising that may coincide or conflict with cultural norms. While some authors credited open declaration of one’s HIV status as a stigma reduction strategy, Vinh-Kim Nguyen (2013) questioned if the conscious-raising and communality of HIV self-confessionals, which is grounded in Western individualist culture, may be incongruent with collective cultures in many African contexts where one’s self-declaration can impact family as well. African women living with HIV may also be less inclined to disclose because of intersecting systems of oppression. Other experiences of discrimination that African women living with HIV may experience — due to gender, race, nation, and immigration status — may make them less inclined to disclose their HIV seropositivity due to its social denigration (Chambers et al., 2015). Thus, multiple senses of identity and belonging coupled with intersecting systems of oppression may shape African immigrant women’s senses of selfhood and peerhood related to living and identifying with HIV.

Peer work as social care. Political activism, coupled with collective caring, has been the guiding force of HIV-related work as peer work locally and globally (Gillett, 2011). The literature on global HIV responses emphasized that HIV as a health pandemic was originally understood as a series of local epidemics (Irwin, Millen, & Fallows, 2003). Communities disproportionately impacted by HIV played pivotal roles in mobilizing response activities in their regions. For instance, as many of the first patients diagnosed with HIV or AIDS were gay and bisexual men; individuals connected to LGBTQ2 communities, many of whom were living with or caring for
people living with HIV, united together to develop community responses to HIV, including founding community-based AASOs to provide practical support (Public Health Agency of Canada, 2007; Robins, 2004). In regions where HIV encompassed a large proportion of the adult population, individuals who were living with HIV along with the broader community marshaled community resources and organized community care for families affected by HIV to combat the devastating magnitude of social, economic, and cultural impacts (Biehl, 2004; Kaleeba, 2004; Manchester, 2004; Mbali, 2004). In the early days of HIV epidemic, the severity of the epidemic in many communities coupled with the absence of formalized HIV-related care necessitated that people living with HIV mobilize to address local HIV epidemics. In becoming a civic body, people living with HIV developed care strategies for themselves and each other (Lee et al., 2016).

Though HIV epidemics varied across local and regional contexts — populations of interest, impetus of mobilization, practices of care — what they shared were common social injustices that HIV epidemics illuminated. Civil societies played monumental roles to assure rights-based approaches to local and global responses (Lee et al., 2016). People with lived experiences of HIV-related oppressions connected their moralization and social denigration to interconnecting systemic inequities such as classism, sexism, racism and homophobia (Stockdill, 2001). Notably, African women recognized their invisibility as a diverse body of people living with HIV and their hypervisibility as “vectors of disease” (Mbali, 2013). African women argued for greater visibility of women’s perspective such as the gendered particularities of HIV acquisition and risk (i.e. gendered-based violence, economic dependency on male partners and family members, gendered sexual health discussion making), address of sexist HIV discourses, and eradication of gendered glass ceilings where women made up the majority of civil society members mobilizing
HIV response activities yet were underrepresented in paid positions in HIV sectors (Leclerc-Madlala, 2005; Mbali, 2013).

African HIV activists also recognized the links between HIV and legacies of colonization such as the economic insolvency of many “postcolonial” African states after achieving independence, emerging economic dependency on international loan agreements (i.e. Structural Adjustment Programs or SAPs), and how resulting economic insolvency and dependency of many post-colonial states resulted in the underfunding and decimating of public health, health care and social service systems that could stem the spread of HIV (Robins, 2004). Chandra Talpade Mohanty (2003) among others argued that globalized capitalist strategies such as SAPs have institutionalized global inequities between former Euro-Western imperialist states and its former colonies; this consequently fueled the transmission of HIV in many sub-Saharan African countries (Husbands, 2007; Robins, 2004; Royles, 2014).

These interconnections between colonial histories and its legacies has been explored in African HIV activism. In South Africa, the Treatment Action Campaign (TAC), developed rights-based approaches that responded to colonization and globalized neoliberalism. Using educational and mobilization strategies, TAC raised awareness of disparate treatment access between Western states (many of which were former imperialist states) and former European colonies and the role international trade agreements played in assuring the monopolization of Western pharmaceutical corporations and the resulting supranational inequities in treatment access (Robins, 2004). Additionally, many African activist organizations drew from anti-colonial

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8 I use the term “postcolonial” to refer to transitions in imperialist rulership (i.e., from direct imperial rule of a colony to autonomous state) and to indicate historical periods when these transitions occurred (i.e., starting in the 20th century for many sub-Saharan African states (Young, 2001)). However, “postcolonial” is a contested term in the anti-colonial literature as it evokes that we are “past” colonialism although colonial legacies still remain in supranational power relations reified within economic, material, and political orders, and in the transnational social positioning of Indigenous peoples and people who descend from former colonial states (Smith, 2012)
movements to ground their own rights-based activism. For instance, many African activist movements used “struggle symbolism”: re-appropriating the discourse and performative styles of liberation struggles and anti-apartheid movements to emphasize HIV mobilization interconnection to postcolonial liberation rights (Mbali, 2013).

Canadian community-based organizations created with, for and by people who identify as African, Caribbean or Black (ACB) have also served as central sites for anti-colonial and rights-based approaches to HIV. Like their African counterparts, Canadian ACB AASOs have recognized the colonial legacies of HIV such as the misrepresentation of HIV in communities of African descent, the erasure of cultural care frameworks, and the need to ensure the active participation of ACB community members in the delivery and design of their care (ACCHO, 2010)

Thus, HIV activism emerged internationally as a human rights response: to address HIV-related oppressions, advocate for treatment and financial support from national and international governments, and address social injustices contributing to infection rates such as interlocking systems of oppression, patriarchy, colonialism, state and supranational income inequities and globalized neoliberalism.

**The greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MEPA)**

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS.” (The Advisory Committee of the People with AIDS, 1983, The Denver Principles, para. 1)

GIPA grounds the formal involvement of people affected by HIV in its responses. The promotion of GIPA strives to eradicate misconceptions of HIV, address HIV-related
oppressions, and embolden people to actively participate in HIV responses regionally, nationally, and globally (UNAIDS, 2007). The idea behind formally recognizing GIPA first emerged as the Denver Principles in 1983 where an advisory committee of people living with HIV voiced the principle to mandate their participation. This was followed by the Montreal Manifesto which called for an international code of rights (AIDS ACTION NOW! & ACT-UP, 1989; The Advisory Committee of the People with AIDS, 1983). GIPA was formalized at the 1994 Paris AIDS Summit and universally adopted by 192 United Nations member countries in 2006 (UNAIDS, 1999, 2007). A greater focus on HIV involvement as meaningful work for people living with HIV has contributed to HIV discourses that emphasize its personal and social meaningfulness, including MEPA or meaningful engagement of people living with HIV, a term commonly applied alongside GIPA.

At its most basic level, GIPA/MEPA recognizes the contribution of people living with or impacted by HIV in the development of response activities: policy development, program development, treatment roll-out and preparedness, campaigns and public speaking, leadership, support, and advocacy (UNAIDS, 2007). Integral to GIPA/MEPA is the active involvement of people living with HIV in addressing the epidemic; these principles outline an agenda for the self-determination, empowerment, and equitable participation of people living with HIV (UNAIDS, 1999). Though GIPA/MEPA serves as an overarching principle for HIV movements internationally, its operationalization is context-driven and should be adapted to regional, political and social contexts (UNAIDS, 2005).

Though HIV mobilization within the West, such as the “Denver” principles and “Montreal” Manifesto, has often been credited as the impetus for the greater involvement of people living with HIV, there has been considerable transnational cross-pollination amongst local civil
societies. The literature on HIV activism emphasized how responses from Africa became *globalization from below* (Appadurai, 2000), or how HIV response activities led by African people living with or impacted by HIV inspired other strategies worldwide. For instance in Uganda, The AIDS Support Organization (TASO), an organization founded by people living with HIV and their family members made significant contributions to reducing HIV transmission rates in Uganda (Kaleeba, 2004). Originating as a support group of sixteen people, TASO evolved into a community-based organization internationally renowned for its innovative support care and group work practices (UNAIDS, 1999; TASO, 2014). TAC, an organization led by people with HIV, is internationally renowned for treatment activism. TACs rights-based strategies of transnational mobilization using social media, networking, international conferences, and timed campaigning in multiple locations inspired U.S. activist groups, such as the AIDS Coalition to Unleash Power (ACT UP) to engage in radical activism to spur government action (Mbali, 2004). Local feminist movements in Africa also galvanized the global organization and transnational activism of women living with HIV; for instance, many of the founding members the International Community of Women Living with HIV (ICW), a global network of women living with HIV come from continental Africa. ICW has been monumental in shaping women-based HIV agendas across local responses and amongst global players like the United Nations (ICW Global, 2011). HIV mobilization is a transnational movement, and varied local contribution, including civil societies and its members in African nation states is laudable (Lee et al., 2016).

**Social relations of peer work.** Local and global HIV activism has mutually informed each other in many respects, and yet, there is some debate as to whose contributions have been recognized. Peoples of African descent have critiqued the Euro-Western supremacy of HIV narratives that ignore or peripherize their active engagement, or solely credit AIDS denialism to
leaders of African descent (Husbands, 2007). HIV activist narratives constructed within the Euro-Western eye often ignore the civil society leadership that emerged from continental Africa and the African diaspora\(^9\) and their seminal role in building grassroots responses and mobilizing governments to act (ACCHO, 2010; Royles, 2014).

Women have also noted that their contributions still remained on the periphery of HIV movements and that their contributions are often lauded within frontline roles such as caregiving, but women are limitedly utilized within leadership and policy activities (Manchester, 2004). Suzanne Leclerc-Madlala (2005) was critical of constructions of women’s involvement in Africa, where their engagement as caregivers had been hailed as leadership. She cautioned governments to distinguish between “leading carers” and “caring leaders” (Leclerc-Madlala, 2005, p. 34): while the former refers to the role of women in leading caregiving responsibilities, the latter refers to their approach to leading HIV response activities. She emphasized that hailing women as leading carers may vindicate their caring work, but it diverted attention away from the dearth of women’s leadership, and that the balance of power within HIV movements resided in men (Leclerc-Madlala, 2005). Formally recognizing African women as leaders within formal HIV responses however, may divert attention away from their informal leadership within civil societies. African women have founded organizations, led rallies, and established care infrastructure often in the absence of funding or governmental aid (Epstein, Morrell, Moletsane, & Unterhalter, 2004; Manchester, 2004).

The Canadian literature also questioned whether peer representation in HIV-related work reflected its diversity. Eric Mykhalovskiy (2008) pointed to the classed relations of HIV. Roy

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\(^9\) I use the term African diaspora when referring to peoples of African descent who are living outside of continental Africa; yet, I also acknowledge the political usage of this term: to collectivize peoples of African descent because of a shared ancestry, and to recognize a collective experience of displacement due to historical and current practices of colonialism that originated in the African continent. (Gilroy, 1993; Zeleza, 2005).
Cain and colleagues (2013) concurred and suggested this elitism coupled with Eurocentrism is demonstrated within peer work, where those who acted as peer leaders tended to be of European descent and relatively well-educated. Within activist movements where racialized women are involved, there were often “systems of privilege” (M. Alvarez & Candelario, 2001), where the dominant voices from the margins shaped rights movements: within feminist movements it was White women or Western women; within African nationalist movements, it was African men; and within HIV movements, it was Euro-Western men. Notwithstanding the increasing diversity of people working in AASOs, including the growing presence of African women living with HIV, issues of racism, sexism, and Eurocentrism persist.

While peer identities and collectivities have shaped civil societies responses to HIV, for African women living with HIV, their mobilization can stem from varied cultural identifications that articulate local and transnational social relations of gender, race, ethnicity, nation and HIV. Even within HIV movements, a form of activism grounded in social justice, there remains hierarchies of peerhood: certain social groups become the representatives of HIV movements and one’s positioning as peer workers reify local and transnational hierarchies.

**Caring through Professional Work**

Stephanie Urdang (2006) suggested that women’s ability to experience social justice is linked to their economic empowerment. For African women living with HIV, the ability to sustain themselves and others can be tied to their paid work in the HIV sector. Through their HIV-related employment, they may support their homeland-based families through material remittances financed through their HIV-related employment. Yet, within the global neoliberal context, caring work as employment becomes a socio-moral responsibility: active engagement in care work becomes civic responsibilities that allow the devolution of social welfare states.
worldwide (Hernandez & Bibler Coutin, 2006). In this vein, the HIV-related employment of African women living with HIV can become a civic duty to three social bodies: capitalist production and market participation within the Canadian labour market, economic exchanges vis-à-vis remittances to one’s African homeland, and community engagement and social reproductive labour within local HIV movements.

The literature highlighted the possibilities and tensions of HIV-related work as caring through professional work: the distinctions of HIV-related work as paid work, the tensions of paid AASO work and “professional” identities, and the peer and professional boundaries African women may have to navigate through their work, and its emotional labour.

**From community space to care institutions — the shifting mandate of AASOs.** HIV-related work grounded in HIV activism forged the formalization of community-based organizations (CBOs), including AASOs and their integration within health and social service infrastructures (Leclerc-Madlala, 2005; Public Health Agency of Canada, 2007; Swartz & Colvin, 2015). Increasingly, the retreat of social welfare and the transfer of institutionalized care to community settings has expanded the demand for community-based care, and some scholars have started looking at HIV-related work as an institutionalized caring practice, particularly from the purview of community-based institutions, and people living with HIV who are employed in them.

AASOs as community organizations often act as an intermediary between informal and formal care settings. For many people living with HIV, AASOs mediate formal care — accessing health care and social services systems, translating complicated health care regimes, navigating immigration and other governmental systems — thereby providing a gateway to information, education, care and support. As community-based institutions, AASOs serve as a space where
caring work as peer work can happen. AASOs act as community spaces where people living with HIV can exchange knowledge, gain instrumental support, and commiserate amongst others with lived experiences of HIV. AASOs as a social space, buffer HIV-related oppressions and fosters social inclusion of people living with HIV (Lovell & Rosenberg, 2011). In this milieu, the community engagement centered within AASOs became a “collective epistemology” (Mykhalovskiy, 2008, p. 153) or a peership model of knowing through belonging with other people living with HIV.

**The context of professionalized peer work in the neoliberal market.** Yet, the literature also pondered the diminishing grassroots community care responses within AASOs given the neoliberal context of health and social service work. Neoliberal ideologies have become popular global economic paradigms, centred on individualism, freedom of choice, market security, laissez-faire economics, and minimal government (C. McDonald, 2006; Parker Harris, Owen, & Gould, 2012). The role of state governance is to allow the market to function using policy to facilitate market competitiveness, encourage labour-market engagement, and reduce government expenditures (Peck & Theodore, 2000). Though neoliberalism is not a new ideology, it has gained prominence due to escalating concerns of many nation-states that they cannot afford social welfare in its current form. Neoliberalism has contributed to increased reliance on civil societies and its actors to supplement the delivery of social welfare through community service and voluntary labour (Ilcan & Basok, 2004).

Though AASOs initially functioned as a space for self and community caring, many scholars questioned if the professionalization of AASOs shifted its mandate away from its grassroots origins towards an institutionalized model of health and social care befitting the neoliberal marketplace. Roy Cain (1993) argued that Canadian AASOs have moved towards a professionalized
model of care as they fight for survival within an increasingly competitive social service “marketplace”. This public institutionalization of informal care responses parallels many African contexts. Nina Hunter (2006) suggested that in response to public health care deficits in sub-Saharan Africa, informal caregiving has become embedded within the public healthcare infrastructure and adopted within state policies and programs. Even HIV activists have become institutionalized. As Barbara Lee and Kate Thomson reflected on their own transitions from HIV activists to state representatives, from grassroots participants to NGO administrators, they highlighted how many leading activists in the early days of HIV movements served as representatives within state governance, international NGOs or private health institutions instead of continued leadership of civil society responses (Lee et al., 2016). The literature raised questions about the depoliticization of HIV response activities due to the increasing professionalization and institutionalization of civil societies and its members. In the milieu of globalized neoliberalism, diminished social welfare states and limited funding for non-profit organizations, the literature suggested that CBOs worldwide, including AASOs in North America and sub-Saharan Africa, have depoliticized their mandates to better assure funding from governments, private donors, and regional and international funders (Batliwala, 2012).

Professional boundaries and multiple identities of peer employees

“...it’s like to have HIV in your home and your body and your job.” (Poindexter, 2006, p. 50).

The literature on HIV-related work suggested that the transition of AASOs into government service providers heightened professional expectations of employees living with HIV. This literature used the language of “multiple hats” and “boundaries”: employees living with HIV were expected to represent themselves as peers while distinguishing themselves from clients (A. T.-W. Li et al., 2015; Poindexter, 2006). Employees living with HIV were also bounded by
professional protocols, yet this divided them from clients living with HIV (Cain, 1993). In contrast, these boundaries were often enforced, permeated, and traversed: employees living with HIV were expected to represent their AASOs, declare their peer status, focus their energies on their work while participating on other work projects as researchers, advocates, and spokespersons. The boundaries can become complex for African women employees living with HIV as their roles exist between peer and professional, although bound to the expectations of both.

African women employees living with HIV may experience a “dual-identity problem” (Poindexter, 2006, p. 56) requiring care from AASOs — which they are entitled to as people living with HIV — but unable to access it as professional workers. For instance, employment could symbolize self-sufficiency which may deter employees living with HIV from seeking care (A. T.-W. Li et al., 2015). Employees living with HIV could also be reluctant to access support services, such as food banks or income supports, for fear how other who know their employment status may perceived their receipt of social assistance (A. T.-W. Li et al., 2015). The informal care once derived from other people living with HIV may also become inaccessible due to professional boundaries. These boundaries could limit one’s ability to talk about work-related stressors with friends who are also agency clients (Muchenje, 2013).

Saara Greene (2013) problematized dual identities and boundaries within the professional roles of peer employees. For instance, the peer researchers discussed in her paper were expected to use their peer identifications when engaging with research participants yet be mindful of professional boundaries in their conduct. Sometimes their obligations as employees and peers were in conflict; while research ethics implored confidentiality of information, from a
community perspective, not conveying potentially beneficial information gleaned from research may feel immoral (Greene, 2013).

African women living with HIV may also have a dual nationalized identity problem: engaging two national cultures — African homeland, Canadian residential land — and navigating their divergent, even discordant care work practices. For instance, cultural precepts of community care, such as providing material support to community members in need, may be discouraged within professional encounters (Greene, 2013). Even so, African women from communal cultural may feel obligated to care for people with whom they identify even if it crossed professional boundaries. In fact, caring for one's community as an African AASO worker may be perceived as a cultural obligation to one’s homeland or ethnoracial communities (McLane-Davison, 2015; Swartz & Colvin, 2015).

Other authors illuminated the multiple care responsibilities — within and outside of the HIV sector — that African women living with HIV may fulfil as familial caregivers, community members, and AASO employees. Poindexter (2006) used the metaphor of two hats to identify the dual nature of HIV-related work where employees living with HIV can be service users and service providers. Her study illuminated the multiple hats of HIV-related work and its corresponding caregiving responsibilities. As noted by Poindexter (2006), women living with HIV who were employed in AASOs carried a “fourfold burden” (p. 47): living with HIV, caring for family, being in the workforce, and having a job working with others living with or affected by HIV. Moreover, they could also fulfill other care responsibilities: caring for the health and well-being of their children, which may include parenting children living with HIV, caregiving of intimate partners or other family members, along with caring for their own health (Poindexter, 2006). As Poindexter illuminated, the multiple hats that African women living with HIV wear
could be numerous since they often occupied multiple working roles: as intimate partners, mothers, family caregivers and employees in the HIV sector.

There was also the institutionalization of wearing multiple hats, where the performance of one’s peer role(s) became additional work obligations. For example, within work that has social justice foundations, there could be implicit expectation that one engages in performance work — advocacy or activism on behalf of community interests. In operationalizing GIPA/MEPA within workplaces, performances of one’s peerhood — people living with HIV representing themselves as peers — may become integrally tied to their working role. While people living with HIV could desire embodying the principles of GIPA/MEPA as paid workers who are actively engaged in AASOs, it might demand performing HIV in all aspects of their lives, including the workplace (Poindexter, 2006). There might also be expectations to represent their AASO workplace outside of work hours, such as attending agency or community events, presenting at conferences, or acting as a community advisor on research projects. While agencies might provide time in lieu, they may not have the human resources to reassign work. Peer performance work could become another work task along with the everyday requirements of the job. Given the depoliticization of AASOs, where activism became less tied to agencies’ mandates, peer performance and activism occurring outside of one’s paid work responsibilities could contribute to multiple jobs, with only one job receiving financial remuneration (Baines, 2004, 2011).

**The financial precarity of HIV-related employment.** While employment may remunerate African immigrant women’s HIV-related work, it did not necessarily address income precarity. Some people living with HIV are employed in contract or part-time positions; others are working in jobs where the hours are flexible but intermittent, such as research work, where the hours depended on variable workloads (Loutfy et al., 2015). Employment may not provide
health-related work benefits such as dental care, drug care, and supplemental health care, or short-term or long-term leave (Catherine Worthington et al., 2013). The unsureness of employment due to lack of job security or limited employment-related benefits while living with cycles of wellness and illness could contribute to people living with as HIV seeing themselves as unable to work due to the episodic and chronic nature of HIV illness (Vick & Lightman, 2010).

Given the precarious nature of social and health service work — including HIV-related caring work — African immigrant women could be gainfully employed and living in poverty (Baines, Cunningham, Campey, & Shields, 2014). As immigrant women, they could be the “breadwinner”, the sole or primary income earners for their family in Canada and in their homeland (Yesufu, 2005); yet, their precarious incomes may not be enough to sustain themselves and their transnational families. Thus, precarious work along with their roles as transnational mothers and breadwinners could add another dimension to the caring labour of African women living with HIV.

**Emotional sustenance and labour of professional HIV-related work.** HIV-related work is also emotional work. Anger, grief, sadness, affection, and love — these emotions fuel HIV movements. Yet this emotional work can take its toll, particularly if the emotions that underlie African women’s gravitation to AASO employment intertwine with their responsibilities as professional workers. The literature on professional HIV-related work illuminated its emotional demands: the work-related stressors of working in a field from which you receive service, with service users with whom you identify, within an organization introduced through personal affiliations.

Caring work within the HIV sector was characterized by high levels of stress, emotional burnout, multiple losses and bereavement, and intense client connections (Kerr, Miller, Galos,
Love, & Poole, 2013; Poindexter, 2006). Additionally, the emotional burdens of HIV-related work could become heightened within professional spheres. Employees living with HIV may find it difficult to maintain emotional and physical health within the high-pressured and stressful AASO work environments (A. T.-W. Li et al., 2015). As people living with HIV, they often had to circumvent the emotional burden of loss: grieving over colleagues and friends who had died, or been deported (Poindexter, 2006). These burdens often intersected with caregiver burden and secondary trauma, particularly when one’s professional responsibilities included supporting those enduring similar concerns. Moreover, the wearing of multiple hats can increase stress loads, as well as exact an emotional toll (Poindexter, 2006).

The emotional connections African women living with HIV may have to caring through HIV-related work was also illustrated in the literature. These connections could become sustenance, where caring for others nurtured the caregiver. The literature specific to women’s HIV-related work hinted at *othermothering* work (P. H. Collins, 2000) where caring work engaged maternal practices amongst those who are not blood relations (M. Alvarez & Candelario, 2001; McLane-Davison, 2015). Through their HIV-related work, African women living with HIV may perform a familial role to communities to whom they identify: homeland communities, communities of African descent or broader HIV communities. Yet like motherhood, these labours of love can become laborious if proper supports are not available to sustain the caregiver.

**Caring Work as Women’s Work**

The HIV literature on caring work expressed both the possibilities and tensions of caregiving for African women living with HIV given its cross-cultural naturalization as *women’s work*. Yanqiu Rachel Zhou (2008) proposed that women’s experiences of living with HIV should
be framed as potentially fulfilling cultural conception of “womanhood” where gender roles and patriarchal constructions of care obligations reify social relations, sociocultural gender norms and roles, unequal power relations, and constructions and expectations of caregiving. Moreover, conceptions of womanhood are constituted within transnational social fields in which African women care and across multiple patriarchal contexts of caring work as “women’s work”.

While there were tensions of womanhood as naturalized gender constructions expressed in caring labour, the literature also suggested that these gendered evocations could also be reframed as activism that emboldened women living with HIV to actively participate on their own terms (M. Alvarez & Candelario, 2001). In this vein, womanhood symbolized a women-centered approach to HIV mobilization. Moreover, motherhood could sustain women and their families from the socially isolating and denigrating aspects of HIV and intersecting oppressions (Shambley-Ebron & Boyle, 2006). The literature highlighted the possibilities and tensions of HIV-related work as women’s work: the invisibility of women-centred perspectives of HIV and caring work, and the reframing of gender identities and collectivities vis-à-vis activism and motherhood.

The lady vanishes: Womanhood in the context of HIV and caring work. The invisibility of women’s perspective of HIV and its care work was a common theme across the transnational literature. For instance, the gendered nature of HIV-related caregiving remained politically invisible in policy although prominent in civic role delegation (Leclerc-Madlala, 2005). In countries where HIV coupled with diminished social welfare states created a caring crisis, women — including women living with HIV — overwhelmingly took on caregiving roles with limited governmental support (Upton, 2003). In Canada, HIV-related care work has become increasingly gendered, with a growing number of women engaged in caring work such as
personal support work, counselling, and front-line roles, and less so in policy-making and leadership roles. Alison Carter and colleagues (2015) emphasized that this gendered glass ceiling within the Canadian HIV sector limited women’s meaningful participation in HIV responses including as leaders within local AASOs. Thus, a movement born from rights activism has become increasingly gendered as a work sector.

Within the context of HIV, women’s perspectives often vanish. Women’s HIV-related concerns are typically not the foci of HIV responses. The lack of women within leadership roles has contributed to a deficient women’s perspective in HIV movements (Gahagan & The Gathering of Spirits Collaborative, 2013). Moreover, the gendered particularities of HIV-related work were often not considered. For instance, the principles of disclosure within HIV activism typically ignored the context of disclosure for parents, particularly mothers who may be protecting their children from knowing their mother’s or their own status. Non-disclosure could protect one’s children from HIV-related oppressions in broader society, a salient concern given the ramifications of HIV- and intersecting oppression that African women living with HIV often endured (Chambers et al., 2015). As illustrated by Manchester (2004), even women who were HIV activists found disclosing to their children their most salient challenge. While African women activists may be comfortable declaring their seropositive status to strangers as representatives of HIV movements, they may be less comfortable disclosing to those close to them.

**Peerhood as womanhood.** While some of the HIV and work literature highlighted the invisibility of women living with HIV as leaders in local HIV responses, the transnational HIV literature offered ways in which African women living with HIV subverted their erasure and activism became transnational feminist praxis. Activism amongst women often emerged to
address the lack of supports available for them, their families, and their communities (Mbali, 2013). Local collectivities of women affected by HIV spearheaded broader activism that addressed social issues that intersected with HIV, such as economic dependency, poverty, and women’s social status within local and global patriarchies (Jungar & Oinas, 2013). Jo Manchester (2004), a leader in HIV movements, emphasized that women’s HIV-related activism became transnational responses guided by local experiences of living with HIV. Much of that work started in Africa. First, as women’s groups within sub-Saharan communities, then at social gatherings at international AIDS conferences. Women often used international conference to convene gender-exclusive meetings amongst delegates, thereby developing transnational mobilization with, for and by women with HIV (Manchester, 2004). The transnational feminist praxis that emerged from women’s HIV-related work was framed by a feminist politic as it deconstructed discursive and material realities constituted within patriarchal power relations (Mbali, 2013).

The literature exploring the HIV-related work of African women living with HIV suggested that their roles as peers or activists might not embody dominant notions of HIV peerhood or activism. Instead, Marina Alvarez and Ginette Candelario (2001) recommended activism that was culturally congruent with women’s ways of being in the world. They offered kinship caregiving: caring amongst other women within similar lived experiences as quiet activism (M. Alvarez & Candelario, 2001) mobilization practices that may not be duly recognized within broader HIV movements. Uniting caring with kinship was in harmony with women’s practices of civic engagement in many Africentric cultures where community caregiving became seminal

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10 Africentric refers to ways of knowing or worldviews of peoples of African descent that is founded on their histories, cultural practices, and local knowledges. Using terminology that emphasizes the commonalities amongst peoples of African descent has become part of a broader decolonizing project with, for and by peoples of African

**Motherhood as womanhood.** While some authors commented on women’s caregiving as naturalized, others presented motherhood as a distinct role in the lives of women with HIV. The denigration and social exclusion that can stem from racialization, racism, xenophobia and HIV-related oppressions could leave African women living with HIV feeling marginalized, socially isolated, and uncared for. The love of their children might become the most stable emotional force in their lives. Shambley-Ebron and Boyle (2006) proposed *strong mothering* where maternal roles and practices could serve as self-care for women of African descent living with HIV. Many authors suggested that the strong mothering construct derived from a tradition of strong women within many African descent cultures that has been generationally passed down by listening to, observing, and modeling one’s female ancestors (Barriteau, 2008; P. H. Collins, 2000; Mekgwe, 2008). Strong motherhood in the context of intersecting systems of oppression could also become racial uplift for peoples of African descent: to better assure their resilience and resourcefulness in the face of intersecting oppressions (McLane-Davison, 2015). Strong mothering recognized the meaningful, purposeful, and holistic aspects of mothering which can serve as self-, familial and communal care.

While the literature conceptualized strong mothering as culturally congruent care for African women living with HIV, these affirming constructions are also constituted within patriarchal and racialized constructions of caregiving as African women’s work. While motherhood identities can validate the self-worth of, and bring purpose to African women living with HIV, Shambley-

descent centered on cultural affirmation, reclamation, and consciousness (Asante, 2016; Chambers et al., 2017; Este, Bernard, & Mullings, 2019 (Anticipated); Mkabela, 2005)
Ebron and Boyle (2006) also suggested that motherhood identities articulated gendered responsibilities of caring work. Social constructions of motherhood were also indicative of gendered notions of women’s self-sacrifice in order to meet the social obligations of caregiving (Zhou, 2008). Moreover, the naturalization of racialized immigrant women, including women of African descent, as mothers-of-others — fulfilling caregiving tasks on behalf of non-kin — has been reified in the transnationalization of caring labour, where immigrant women who immigrated to Western countries addressed care deficits through formalized care work (Pyle, 2006). As Joan Tronto (2011) recommended, to consider motherhood and other forms of caregiving as a choice rather than an obligation required denaturalizing caregiving as women’s work, and reconceptualizing it as shared social responsibilities that everyone should participate in as human beings.

The literature on HIV and caring work illuminated the many ways in which the HIV-related work of African women living with HIV became caring work within and across the transnational social fields within which they engage. While these illuminations articulated cultural performatives of caring work, they also offered alternative readings of HIV-related work as collectivism, activism, kinship, sustenance and care. Nonetheless, the peer, professional and feminine roles that African women living with HIV may occupy vis-à-vis caring work could reproduce cultural constructions of what they should be and how they should care: as women, racialized persons, immigrants, people living with HIV, activists, community members, and social citizens. These roles indicated overarching ideologies and social performatives African women living with HIV are expected to uphold to belong to a larger collective, which correspondingly paralleled processes of citizenship.
Caring Work as a Citizenship Project

The literature that discussed HIV-related work as peer work, professional work and women’s work highlighted the social relations of caring work at the interpersonal, familial, civic, state, and supranational levels. These relations occurred within a broader social context of work as rights and responsibilities of belonging to a collective: what it meant to care for one’s community, and what it meant to be a citizen. According to Will Kymlicka and Wayne Norman (1994), “citizenship is not just a particular status, defined by a set of rights and responsibilities. It is also an identity, an expression of one’s membership in a political community” (p. 369). In this vein, citizenship extended beyond one’s legal rights to belong, it became active processes of demonstrating one’s membership. The citizenship literature theorized what it meant to belong such as people’s perceived membership to a social group based on common histories, shared values, and accepted social norms; consequently, membership required fulfillment of activities or duties on behalf of the collective. The citizenship literature theorized what it meant to be a “citizen”, who receives that designation, and what it entailed including the identities, roles and obligations that correspond to one’s citizenship designation (Lister, 1997). The literature on citizenship positioned caring work as practices of civic engagement, where caregiving activities contribute to the social well-being of civil societies, its members and society at large (Crick, 2000; Herd & Meyer, 2002) In this vein, caring for one’s community through HIV-related work is not only processes of identity formation and communal belonging, but obligations of membership.

Three branches of citizenship literature conceptualized HIV-related work as rights and responsibility of communal belonging: active citizenship defined as realizing one’s social rights and obligations to a populace (e.g., neighbourhood, city, or state) through social participation (Onyx, Kenny, & Brown, 2012); health citizenship, conceptualized as rights-based identities, collectivities
and responsibilities where one’s civic engagement as a member of a health-impacted population became oppositional consciousness and empowerment (Shaw, 2012); and *transnational citizenship*, which assumed that members may be embedded and engaged within more than one nationhood and their membership rights and responsibilities activated across transnational social fields (Glick Schiller & Fouron, 2001).

**Active Citizenship.** The literature understood active citizenship as social participation that contributed to society and its members (Fuller, Kershaw, & Pulkingham, 2008). Active citizenship presumed reciprocated responsibilities of civic belonging: community members were expected to demonstrate their allegiance through cultural practices, social activities or political participation; in turn, the state accorded members with certain rights (Packham, 2008). The literature of active citizenship often referred to the work of Thomas H. Marshall (1950, 2009), whose notion of citizenship comprised civil (i.e., personal liberties and freedoms), political (i.e., rights to exercise one’s political obligations such as voting rights) and social aspects (i.e., rights to social welfare, and to be included as a member, and be treated equitably). Marshall’s concept of social citizenship recognized the state’s responsibilities to realize people’s rights, including assurances of social welfare, expansion of civil and political rights, and social inclusion of members who have been excluded or marginally included (Marshall, 2009). Bernard Crick (2010) offered active citizenship as a realization of T.H. Marshall’s vision where members had a social and moral responsibility to actively engage through civic participation. Civic engagement has become a key aspect of active citizenship where individual, groups, and community organizations actively participate in realizing the civil, political and social rights of its members.
and consequently become collectively responsible for caring for society at large (Rice & Prince, 2013).

Given its simultaneity of caring — people living with HIV realizing their rights to social welfare, and a reciprocated “giving back” to society through AASO work participation — HIV-related work embodies the tenets of active citizenship: where one realizes their rights of social inclusion, and their civic, social and political responsibilities through self- or social advocacy (Crick, 2010). For instance, GIPA/MEPA recognizes the rights of people living with HIV to be meaningfully engaged in HIV response activities; accordingly, such social engagement betters the communities to which people living with HIV belong. Correspondingly, HIV-related work of people living with HIV achieves state mandates of HIV prevention, treatment, care and cure. For African women living with HIV who work in Canadian AASOs, their active participation in Canadian AASOs can become transnational civic reciprocation: socially contributing to Canadian society through civic participation and “giving back” to homeland communities through knowledge transfer, social networking, and transnational activism.

Many theorists argued, however, that the ideals of active citizenship were unattainable given its liberal ideologies, gendered, racialized, nationalized, and ablest notions of social participation, and privileging of Euro-Western ideals of social participation (Fraser & Gordon, 1992). For instance, active citizenship is premised on patriarchal models of social participation (i.e., breadwinner model of work) (Fuller et al., 2008). Care work often existed as invisible civic engagement, poorly recognized for its social contribution and minimally supported by the state (Herd & Meyer, 2002). Active citizenship tied to nationalist ideologies often articulated dominant norms of the citizenry which correspondingly determined one’s positioning within the collective (Yuval-Davis, 2007). Lloyd L. L. Wong (2008) pondered the tensions of active
citizenship on behalf of one’s homeland while embedded in Canada, as it could be perceived as practising “thin citizenship” (p. 80), actively demonstrating one’s loyalty to another country which diminished one’s sense of belonging to Canada. The recent policymaking discourse in Euro-Western nation-states post 9/11 has contributed to perceptions of thin citizenship, where the national loyalty of immigrants is questioned when they are actively engaged in their homelands, particularly when homeland nations are not Western states (L. L. Wong, 2008). For people who are not members of privileged social groups — White, Western-born, and gainfully employed — they bear a greater responsibility to actively participate in ways that are socially idealized (Yuval-Davis, 2007). For African women living with HIV, they may adopt ways of participating in AASOs that embody ideals of Canadian civic engagement — depoliticized advocacy, labour market engagement, reduced reliance on social assistance among other Western liberal performatives — to better assure their belonging in Canada.

The citizenship literature also questioned the reciprocal nature of active citizenship in the context of globalized neoliberalism. Notably, the literature on civic participation in CBOs questioned if active citizenship has responsibilized civil societies: governance that divest states’ civil, political and social duties to community-based organization (Ilcan & Basok, 2004; Wakefield & Fleming, 2009). Paul Crawshaw (2003) argued that active citizenship in the neoliberal context typified governmentality; self-governance and promotion of one’s civic engagement became aspects of state control (Rose, 1999). The formal institutionalization of active citizenship engagement via state sanction or promoted community engagement risked making community organizations and its members responsible for assuring their rights; in turn they had a duty to participated in activities that promoted their own and their communities’ wellbeing (Shaw, 2012). Moreover, shifting responsibilities of community betterment imperiled
communities with being regulated, manipulated, or surveyed by the state: as such, the discourse of empowerment such as GIPA/MEPA could become moral technologies that regulated and surveyed civil engagement (Crawshaw et al., 2003). In this vein, the state's promotion of active citizenship operated as a guise to devolve social welfare to civil societies and its members, thereby increasing citizens’ responsibilities to assure their social rights (Shaw, 2012).

The HIV, caring, and transnational literature on social participation incorporated these theoretical notions of active citizenship to their understanding of HIV-related work as caring work. The literature on health citizenship recognized the possibilities of HIV-related work as realizing the equitable inclusion of people living with HIV and their rights to be cared for by society; conversely, it questioned the politics of active participation given dominant social norms of social participation in neoliberal contexts. The transnational literature pondered HIV-related work as practices of transnational citizenship, and what this may mean for immigrants, including African women living with HIV, who actively care across transnational social fields through HIV-related work.

**Health citizenship.** Health citizenship has been theorized as processes of community empowerment built on notions of civic responsibility, enabling communities to actively engage in their communities to realize their civil, political and social rights (Shaw, 2012). The literature on HIV-related health citizenship aligned with other health rights-based movements — mental health, breast cancer, disability — where critical theories and mobilization approaches from feminist, LGBTQ2, anti-colonial, and civil rights movements shaped mobilization activities around a health concern that disproportionately affected marginalized social groups (Royles, 2014; Shaw, 2012). HIV-related activism has fostered health citizenship as it is centred on forging collectivities and conscious-raising through a biosociality or shared experience of living with
HIV (Kielmann & Cataldo, 2010). Steven Robins (2006) suggested that living with HIV as a health compromising and life-altering experience coupled with HIV-related civic participation could transform identities and subjectivities of people living with HIV: from moralized subjectivities to self-actualized selves, to agents of change. Moreover, active participation alongside other people living with HIV could become self-care strategies that addressed social isolation, marginalization and HIV-related oppressions and fostered self-awareness, hope, senses of belonging, and political consciousness (Robins & von Lieres, 2004). In the intersections of oppositional consciousness and identity-rights, HIV has evolved into a health-rights based movement that subsequently reciprocates care amongst its members.

The literature also cautioned against idealizing health citizenship as empowerment and rights attainment given the neoliberal contexts within with public health care is provided. Franco Barchiesi (2005) argued that the discourse of community empowerment rationalized the state's devolution of care to communities and families. In this context, the downloading of health services to civil societies became reframed as rights-based, increasing workloads for AASOs and its workers under the guise of capacity building and self-empowerment. According to Karina Kielmann & Fabian Cataldo (2010), the evolution of HIV-related work as “therapeutic citizenship” (p. 23) was situated at the intersections of public care system and community rights; it embodied the ideals of GIPA/MEPA — to actively and meaningfully involve people living with HIV as AASO workers — yet this realization of community rights subsequently came when healthcare systems locally and globally reduced their role in social welfare delivery and transferred care responsibilities to civil societies and its members.

The tensions of health citizenship as community responsibilization can be difficult to discern as the impetus to be civically engaged often stemmed from cultural values of reciprocity and
corresponding expectations of communal membership. Alison Swartz & Christopher Colvin’s (2015) study of HIV community care work in South Africa highlighted how naturalizing discourses of care emerged in South African HIV care workers sensemaking of their work. For instance, many of the volunteer care workers suggested that as Africans, care work was “in our veins” (p. 142), or a natural capacity and obligation to care for people from one’s local community given the communality and moral responsibilities to care for others are valued within their local cultures (Swartz & Colvin, 2015). The authors attributed what they defined as an “African-ness” of caring to the principles of Ubuntu common in many Southern African cultures (Swartz & Colvin, 2015). Ubuntu emphasized the importance of communality, relationship and reciprocity, and that one’s sense of self was integrally tied to other human beings (Tutu, 1999). While they recognized the value of caring as a cultural precept, they also questioned that such cultural narratives served as naturalized discourses (Swartz & Colvin, 2015). Correspondingly, these naturalizing discourses intersected with the feminization of HIV caring work in Southern African contexts (Urdang, 2006). While health citizenship could realize a sense of reciprocated belonging amongst people living with HIV, for African women living with HIV such civic participation could also articulate performatives of caregiving.

**Transnational/translocal citizenships.** The HIV literature suggested that HIV-related work transcended notions of nation. For instance, James Gillett (2011) among others have emphasized how local HIV responses became transnational active citizenship such as cross-national mobilization or attending international conferences to forge senses of solidarity amongst people living with HIV worldwide. Civic participation could also be *translocal,* where
one political, civil, cultural or social practices derived from or responded to homeland contexts of HIV while geographically embedded in another nation-state (L. L. Wong, 2008).

Nina Glick Schiller & Georges Fouron (2001) suggested that continued engagement within one’s homeland while embedded in another nation-state existed as active claims to homeland citizenship. Social networking amongst people living with HIV who shared homeland ties, political participation in homeland HIV mobilization while living abroad, or continued articulations of homeland values through HIV-related work could assure African women’s continued connections to their homelands. In the absence of culturally congruent approaches to HIV in many mainstream organizations, community-based ethnoracial AASOs in Canada often served as social spaces to translocate back home. For African women living with HIV, ethnoracial AASOs became spaces to activate homeland engagement amongst other African peoples: to give back to homeland communities to which they belong; realize their rights to have their particular experiences of HIV recognized; enact desires for culturally congruent services, and assure experiences of xenophobia, racism and other intersecting systems of oppression were acknowledged within their care (ACCHO, 2010).

The HIV literature also explored the tensions of translocating home through HIV-related work when embedded in a Euro-Western settler state. An overarching tension was the institutionalized colonialism that operated within Canadian HIV responses, where activities centred Euro-Western viewpoints in its responses on behalf of peoples of African descent (Gray, 2015; Husbands, 2007). The tensions of Euro-Western supremacy within Canadian HIV responses could become particularly salient for African women employees living with HIV as it could shape how they engaged within AASOs. Marvelous Munchenje (2013) emphasized that professional boundaries that regulated employees engagement with clients could be incongruent
with homeland cultural practices where there may not be as stark a divide between one’s professional and personal relations. This inability to informally interact and socialize with clients due to confidentiality concerns could isolate African women employees living with HIV from their social network, often sources of instrumental, emotional and social care for immigrants (A. T.-W. Li et al., 2015). Moreover, translocating home within ethnoracial AASO might not necessarily assure African women employees living with HIV received culturally congruent care. As Alan Tai-Wai Li and colleagues (2015) forewarned, given the strong collaborative ties amongst ethnoracial AASOs, African women employees could feel unable to access ACB AASOs because they may be readily known as a worker; yet this inability to access such organizations could consequently deprive them of culturally congruent care.

What the transnational HIV literature illuminated were the possibilities and tensions of HIV-related work as *translocal care work*, an opportunity to realize one’s homeland ways of working on behalf of Canadian responses. Recreating homeland ways of working in HIV response activities — creating ethnocultural AASOs or continued engagement in homeland responses for instance — were strategies African women living with HIV used to translocate back home while living in Canada. This literature also highlighted the difficulties of relocating one’s homeland ways of working within the Canadian AASOs given the continued privileging of Euro-Western ways of active participation and the professionalized boundaries of HIV-related work.

The HIV, care work and transnational literature emphasized how HIV-related work can become self-, communal and social caring for African women living with HIV. Moreover, such caring work occurred within and across transnational social fields. African women’s ways of working in homeland HIV response activities may become translocated within Canadian AASOs; their engagement in Canadian AASOs may become ways to care for homeland-based
family and communities through remittances of material resources, sharing of knowledge, mutual support, and transnational mobilization. Their sense of being and belonging back home can also be place-made through ethnocultural social networks, and local practices of care. In the context of globalized neoliberalism and intersecting systems of privilege, power and oppression, HIV-related work can become responsibilities of belonging within locales and across transnational social fields. These modes of belonging are in turn constituted within the intersections of gender, race, class, immigration status and nation. As such, the literature on HIV and caring work illuminated the varied understandings of greater involvement, meaningful engagement, peer, and community, and care within which African women may make sense of their HIV-related work as caring work. Caring work with, for and by African women living with HIV is correspondingly constituted within historical, cultural, and, geopolitical relations within and across local and transnational context.

Given the literature’s discussion of HIV-related work as peer work, professional work, women’s work, and citizenship work, I recognized that an understanding of HIV-related work as caring work should consider the multiplicity of such caring for African women living with HIV — caring for oneself, one’s family, homeland communities, HIV communities, and other cultural communities — and the simultaneity of caring within and across local and transnational contexts. It also must consider how homeland memories, ideals, values, roles and responsibilities can be translocated within one’s HIV-related work in Canada. Considering the evolving political and social context of civil societies and states’ involvement in HIV response activities, HIV-related work as rights and responsibilities to be actively engaged also needs to be framed within the temporal and local context that such work emerged and continues: how did one become involved in HIV-related work, and how has it shifted and changed in the locales where one
engages? Moreover, caring work as social performatives and agential acts must be understood by their distinct and interconnected elements.

While the literature provided a better understanding of my colleague’s story about working in an AASO because she cared, it also provided a partial one. I wanted to know from other women like her. I wanted to listen and learn from other African women living with HIV who could offer diverse perspectives of HIV-related work as HIV caring work, perspectives that could articulate as well as reframe current understandings of HIV, work, and caring labour.

I also wanted to use knowledge generation as a demonstration that I cared for my colleague, and other women like her. As this study originates from community work, I endeavoured to produce a body of work that “gave back” to the community. Hence, my focus on HIV-related employment and African women’s work in Ontario AASOs as this was identified as prominent issue for the Ontario ACB strategy (ACCHO, 2013). Though I recognize the difficulties of producing a community product from an academic work such as a thesis, I felt it was a worthwhile aim.

Gaps in the Literature

Knowledge gaps. While the literature on AASO involvement of people living with HIV is burgeoning, research on paid work in the Canadian HIV sector is relatively new. The literature emerging from African contexts identified both the opportunities and tensions of turning one’s care work into paid work opportunities in the HIV sector. Swartz and Colvin (2015) study indicated that although HIV-related work was once a labour of love done without financial remuneration, HIV-related employment has become a necessity because of limited jobs availability, and the prominence of international NGOs as employers. Yet, turning such voluntary work into paid positions could disrupt communality in the context of poverty, with
few community members financially benefiting from paid care work in social service
organizations (Swartz & Colvin, 2015). External motivators of caring, such as care work for
money, were discursively framed as incongruent with collective responsibility to care for others
regardless of pay (Swartz & Colvin, 2015).

The literature on AASO employment in North American contexts identified sociocultural
distinctions for racialized people living with HIV such as the tensions of professional boundaries
for employees from collectivist cultures, and intersecting oppressions related to HIV and other
marginalized social locations (Greene, 2013; A. T.-W. Li et al., 2015). Of the studies that have
touched upon the employment of women with HIV in AASOs, they noted the continued
patriarchal nature of HIV sectors; limited work opportunities for women; difficulties balancing
caregiving roles; and the tensions of disclosure, stigma and discrimination as it impacted them
and their families (Carter et al., 2015; Greene, 2013; Logie, James, Tharao, & Loutfy, 2012;
Poindexter, 2006).

The literature also indicated how multiple oppositional consciousnesses — forged within the
intersections of gender, race, HIV, nation and among other social positionings — may shape
how African women conceive their HIV-related employment as caring work. A study conducted
by Denise McLane-Davison (2015) highlighted the meaning of HIV-related employment as
“uplift” for women of African descent who work on behalf of their ethnoracial communities.
She conceptualized their engagement as forms of activism that aimed to address the social
injustices faced by communities to which they belonged, notably communities of African
descent impacted by or living with HIV. Women’s practices of work, such as incorporating
cultural precepts of caring and kinship care, were interconnected to their gendered and racialized
social positioning in Euro-Western society as well as affirmation of the racial and gender identities that they upheld (McLane-Davison, 2015).

The literature on AASO involvement as employment is burgeoning; however, there is limited literature exploring the HIV-related work experiences of African women living with HIV employed in Canadian AASOs. Notably, Denise McLane-Davison (2015) identified a significant gap in understanding the HIV-related employment experiences of African-American women living with HIV, echoing the knowledge gaps in Canada.

**Theoretical gaps.** There is limited literature looking at HIV-related work of African women using a transnational lens. As offered by Tsuda (2012), literature exploring immigrant experiences within settler states is typically bound within border spaces: tying the analytical focus to one nation-state, focusing the analysis within the border spaces between two countries (i.e., migratory practices), or emphasizing the diasporic condition of being away from one’s homeland. What seems to be missing from the literature on HIV, caring labour, and African women living with HIV is an analysis of being both simultaneously in and in-between locales, and how caring work is shaped by these spatial conditions. While Tsuda (2012) critique focused on geography — or exploring experiences of physically migrating from, existing between or being settled or displaced within geographic space(s), I argue that a transnational analysis of HIV-related work of African immigrant women should explore migration, settlement, and displacement as historical, psychic, communal, and cultural. Transnationalism often appears as practices that are interconnected to place or space while not being geographically embedded
within it. Missing from the literature are understandings of HIV-related work as remaking or translocating place through memories, ideologies, value systems and social interaction.

Also absent is a transnationally informed analysis of collectivity and identity vis-à-vis caring through HIV work. Analysis of the experiences of African women living with HIV needs to consider their work experiences in relation to their social histories, transnational connections and current realities as racialized immigrant women living in Canada. This contextualization should include the locales to which they are embedded and engaged as workers as well as the broader transnational context of HIV, work, and caring labour.

**Methodological gaps.** Recently, my methodological work with a collective of Indigenous, African descendant, and allied HIV researchers and community leaders has reflected on incorporating decolonizing methodologies within HIV research (Chambers et al., 2017). I have also conversed with other researchers, front-line workers, community advocates of African descent who like me desired greater use of culturally relevant methodologies that incorporated Africentric worldviews (Chambers, 2019, anticipated). This methodological work troubled the colonial legacies operating in the work that we do in HIV research which Kimberley Gray highlighted in her study exploring the politics of knowledge generation in HIV research on Ontario’s African, Caribbean and Black communities (Gray, 2015). One politic Gray explored was the notion of *epistemic legitimacy*, where academic production of HIV-related research upheld dominant epistemological stances, such as the privileging of post-positivistic epistemologies (Gray, 2015). What Gray’s study illuminated were ways in which knowledge producers of African descent upheld their own stances of epistemic legitimacy. These stances were typically centred on community-relevant knowledge generation, including generating knowledge that unearthed sociopolitical realities of ACB communities, used participatory frameworks, engaged
communities of African descent in knowledge generation and had knowledge producers of African descent taking the lead (Gray, 2015)

These conversations amongst AASO workers of African descent supported by Gray’s research illuminated the relevance of using this thesis — an academic product — to make an epistemic stance grounded in culturally relevant epistemologies. This stance encouraged me to tackle a thesis topic that had utility for the ACB strategy in Ontario (i.e., AASO employment in ACB communities). It bolstered me to incorporate *culturally responsive methodologies*: methodologies and methods that responded to social, political and historical context of knowledge generation for people from colonized cultures (Chilisa, 2012). As such, I endeavoured to embrace knowing practices that reflected upon our — participants’ and my own — ways of being and understanding our social worlds. Ironically, this knowledge generation in contemporary Canadian context translocated the Narrators and my own back homes. My thesis ponders how peoples of African descent bring homeland ways of being in the world to our sensemaking of it, and how homeland ways of knowing can be practiced within academic knowledge generation.
Chapter 3: Ways of Knowing That Guide My Own (Epistemological Framework): Decolonizing, Anti-Colonial and Transnational Feminist Perspectives

My review of the literature on HIV, work and caring labour highlighted the many ways in which HIV-related work could become caring work for African women living with HIV. It also identified the theoretical, conceptual and methodological gaps when framing caring work from their viewpoints. Additionally, the literature illuminated the dominant cultural lenses within which HIV-related work is conceptualized: Euro-Western perspectives often framed from patriarchal standpoints of HIV, work and caring labour. My immersion within the transnational literature alerted me the importance of place and space in understanding HIV-related work as caring work for African women living with HIV. Notably, I referred to literature from continental African contexts to glean a better understanding of what caring work may mean for African women living with HIV who are geographically located in Canada; homeland histories, memories and experiences of HIV, work and caring labour could shape how they made sense of their HIV-related work as caring work.

My literature review also illuminated methodological gaps that became more salient as I pursued my Ph.D. This doctoral study became a space where I pondered knowledge generation: could I produce a thesis that had utility for the communities with which I work while at the same time respond to doctoral program requirements? As a community-based researcher, I am accustomed to using participatory frameworks to better assure that knowledge is co-generated with community members. Participatory frameworks recognize the principles of research reciprocity: the reciprocal nature of knowledge generation, and that the resulting research will honour the varied contribution made by everyone involved (Chilisa, 2012). These are the principles that I bring to the research I conduct. Yet, as I pursued my Ph.D., I started to question if designing a research study that recognized the equitable participation of community
members would be enough to reflect principles of reciprocity. What about honouring community members as knowledge generators in their own right?

I also pondered doctoral research as academic knowledge generation such as the worldviews that dominate the social science fields and how these views guided doctoral knowledge generation. The Ph.D. thesis is recognized as “[an] original contribution to knowledge, as judged by experts in the field.” (Evans, Gruba, & Zobel, 2014, Kindle Locations 380-381). This understanding of a thesis made me question, who are the knowledge generators in this research context? Whose theories are credited? Whose contributions are recognized? Who are deemed experts? These reflections led to questioning my thinking around knowledge generation. What knowledge systems guided my understanding of research as knowledge generation? Who were the human actors engaged in knowledge generation? What discursive messages would my research convey from the ways in which I gathered, interpreted, shared and promoted the knowledge generated? Specifically, this understanding of a thesis — what is knowledge, who are the experts, what is original — made me reflect on the power relations that shaped academic knowledge generation such as the underlying belief systems that guided what knowing practices were deemed scholarly. Too often, Western belief systems, particularly those drawn from European descendant cultures became the predominant ways in which we know, which in turn normalized and idealized Euro-Western worldviews as THE ways in which we should know as doctoral researchers.

Yet, were the ways of knowing privileged within the academy the only way in which I knew? As I reflected upon the ways in which I participated in knowledge generation within the academy, I started to consider the ways in which I generate knowledge outside of it. The diaries I kept. The stories I shared. The pictures I doodled. The poems I wrote. The plays I performed. The family
memories that guided me. The collective histories that underpinned how I made sense of the world. This grappling became *paradigmct troublings*: I reflected on the ways of knowing the world that Ph.D. theses commonly took up. I considered how my thesis could trouble academic knowledge generation. And I grappled with troubling it while generating a Ph.D. thesis.

I also grappled with conducting research that was congruent with ways in which women of African descent, including myself, made meaning of our social worlds. What did that mean exactly? I questioned if this notion of congruency presumed universality. That as women of African descent, the women I interview and myself would share an understanding of racialization and racial consciousness that could easily translate into an “Africentric” worldview. Sotunsa Mobolanle E bunoluwa (2009) suggested that research with and for women of African descent should draw upon the particularities of their experience while recognizing interconnections across continental Africa and the African diaspora. For me this meant connecting to the ways in which the Narrators and myself may have interconnected ways of knowing the world but also being open to them introducing me to new ways of knowing drawn from their local precepts.

My ways of being (ontology) and knowing (epistemology) are grounded in this grappling with and troubling how I know and what I know in relation to others. This relational paradigm considers research methodology and methods as centred on relationships: the research relationship in which we engage, the social relations within which research is conducted, and the power relations of knowledge gathering and sharing. This relational paradigm is also mindful that ways of being, knowing and relating are integrally tied to place. Knowledge gathering and sharing is and becomes placemaking processes — through the narratives that we tell, relate, gather, interpret, and share — that make sense of our social worlds in relation to others.
To process my grappling and troubling, I was drawn to two bodies of thought — transnational feminism and decolonizing knowing from anti-colonial perspectives. Initially, decolonizing knowing guided my methodological approach and transnational feminist theories shaped my analytical approach. But as I engaged in my own sensemaking of methodology and method, and of HIV-related work as caring work, I engaged both bodies of thought in tandem. Decolonizing knowing from an anti-colonial perspective aided my theorization of caring work as articulation and constitutions of colonial power relations within and across local and global contexts. Transnational feminism aided my epistemological sojourning vis-à-vis method: it guided my sensemaking of my ways of knowing the world and how it was provoked and evoked through the story-telling of the Narrators. When combined into a theoretical framework, decolonizing, anti-colonial and transnational feminist thoughts implore Western researchers to move away from interpretations centred upon (Euro-)Western stances and instead, use critical theories from transnational viewpoints to understand the experiences of African women (Mohanty, 2003). As emphasized by Gayatri Chakravorty Spivak (1988), decolonizing, anti-colonial perspectives of transnational feminist thoughts are committed to letting the subaltern speak.

Decolonizing Perspectives: Decolonizing Knowing and Anti-Colonial Thoughts

Decolonizing knowing and anti-colonial thoughts unpack, reflect upon, and challenge colonial power relations, and use knowledge generation as practices of deconstruction, contemplation and conscientization (Chilisa, 2012; Dei, 2012a; Smith, 2012). Arlo Kempf (2009) conceptualized anti-colonialism as explicating colonization in all aspects of local and transnational social relations (e.g., knowledges, economic relations, relationships with the land, migratory movements etc.). Notably, decolonizing knowing and anti-colonial thinking reflects
upon the colonial relations of knowledge generation and reframes research as action-oriented and political (Chilisa, 2012).

Decolonizing and anti-colonial thinkers have suggested that to understand present-day social relations within which peoples of African descent make sense of their social world, it required a harkening back to colonial pasts. Carolette Norwood (2013) remarked that to understand contemporary experiences of racism, sexism, xenophobia and intersecting oppressions, researchers must place them in their colonial contexts. This contextualization required us to recognize how systems of social differentiation, privilege and oppression as experienced by peoples of African descent are grounded in European imperialism, ideological practices that promote the belief systems of the Euro-Western states, and colonization, practices of violence, marginalization, domination, exploitation and cultural imperialism to assure territorial and economic expansion, and social supremacy of imperialist states (Young, 2001). Furthermore, our analysis of contemporary social relations needed to acknowledge we are not “post” colonialism, nor is it “neo” or new. As emphasized by Anibal Quijano (2000) what is currently understood as “globalization” is actually the cumulative coloniality of power: Euro-Western systems of supremacy, domination and exploitation stemming from European imperialism worldwide continued to operate within local, regional and transnational geopolitical relations, economic organization, social positionings, scientific reasoning, cultural practices, and knowledge generation.

As I reflected on historical and contemporary context of colonialism and colonization, I considered their particularities in HIV research on peoples of African descent such as the social conditions that fostered disproportionate rates of HIV in peoples of African descent, and the interconnections between colonial practices of territorial displacement, cultural annihilation,
economic exploitation, violence and slavery, and the prevalence of HIV in continental Africa and African descendent populations in settler states. Despite colonization, people of African descent have prevailed. For example, through my HIV-related work with communities of African descent, I have witnessed their resourcefulness as demonstrated in HIV-related activism, knowledge mobilization and collective care practices. While I recognized the historical and contemporary impact of colonialism on African peoples, I also appreciated their individual and collective agency to resist colonial oppression and to reframe identities, reclaim knowledges, and reaffirm ways of being and knowing outside of the colonial gaze. I looked to theories that critically contextualized the colonial relations within which African women living with HIV must contend as well as agential practices that emerged within HIV-related work. These agential practices included acknowledgement and address of colonialism and colonization within knowledge generation.

In this section, I will discuss the particularities of anti-colonial thoughts and decolonizing knowing and their theoretical relevance for the Because She Cares study. While these theories are interconnected, I define them separately to highlight these distinctions and their theoretical interconnections.

**Anti-colonial thoughts.** Anti-colonialism is a term commonly used to define a political stance against colonialism, its practices and processes (Young, 2001). Often deemed “resistance theories”, anti-colonial theories strive to critically interrogate colonialism and offer resistance measures to address its impacts such as conscious-raising activities, and social mobilization (Dei, 2006). Arlo Kempf (2009) considered anti-colonial thoughts as ways of being (ontological), knowing (epistemological), and morally relating (axiology) with our social worlds. He believed that addressing colonization was a moral stance to which everyone should be accountable.
Moreover, anti-colonialism puts the knowledge of the colonized in the forefront such that their standpoint becomes the purview from which colonialism and colonization are explicated (Kempf, 2009). An anti-colonial reality envisions socially just change: this ontological stance considers social justice as attainable, change as possible, and oppression as defeatable (Kempf, 2009).

Many anti-colonial thinkers engage in active political resistance that coincides with theory building. Frantz Fanon, a Afro-Martinican intellectual, psychiatrist and political activist engaged in anti-colonial resistance. He participated in the Algerian war and its nationalist liberation activities, while writing about the adverse effects of European colonialism (Wretched of the Earth), colonial resistances (A Dying Colonialism), and reclamation of authentic Africentric consciousness (Black Skins, White Masks) (Fanon, 1953, 1961, 1967). Fanon's approach to anti-colonial thinking combined political action with theoretical reflection, and overtly positioned the theorist as a colonial subject striving to decolonize their own mind. Fanon's approach has become emblematic to anti-colonialism: colonial subjects (i.e., racialized scholars) engaging in intellectual work that is unapologetically political and change-oriented.

Anti-colonial thoughts offered analytical approaches that politically interrogate racism and racialization as colonial by-products as experienced by the women I interviewed. Moreover, it gave me the language to politically position myself within this thesis as a person of African descent who mindfully reflected on anti-colonialism throughout my doctoral studies. Consequently, this anti-colonial positioning influenced topical, ontological, epistemological, and methodological choices I made: I chose to focus my thesis on a topic area where colonial relations served as a focal point and analysis drew out these aspects as relevant.
Decolonizing knowing. I also desired theory that was not just theoretical (How can I understanding colonialism and its impact from the perspectives of peoples of African descent?) but reflexive (How can I address and reflect upon colonization within methodology and method?). Notably, I desired theory that strived to decolonize by questioning Western supremacist assumptions within research, developing knowing practices (i.e., methodologies and methods) from the perspective of peoples of African descent, and incorporating methods that were culturally responsive to the ways in which African peoples (as research participants, researchers, and thinkers) knew their social worlds. While I recognize that decolonizing knowing is an ambitious undertaking, I think in the striving, I engaged in this highly reflexive process that supported my grappling with and troubling of colonialism within HIV knowledge generation, including my own knowing practices.

Bagele Chilisa (2012) defined decolonizing knowing as a critical pedagogy, body of thought, reflexive practice, political praxis, and form of consciousness. Decolonizing knowing is a process of uncovering and challenging colonialism within knowledge generation, notably the Euro-Western centrism that predominates in academic knowledge generation. Such knowing contemplates research as a colonial tool, where cultural imperialism of the dominant group is reified and the promulgating of its precepts vis-à-vis knowledge generation becomes tools of colonization (Smith, 2012). For peoples of African descent, decolonizing knowing is often framed as reclamation as it strives to integrate Africentric worldviews within knowing practices with, for, and by peoples of African descent so they becoming “tools of our own” (Lorde, 1984). According to George Sefa Dei (2000) decolonizing knowing strives to decentre Euro-Western knowledge generation to create space for knowing practices often marginalized or excluded from the academy. It attends to the colonial power relations within which knowledge is generated and
aims to address power imbalances within knowledge gathering, interpretation and sharing (Dei, 2012a).

Key to my understanding of decolonizing knowing was decolonizing my mind or troubling the Euro-Western imperialism I’ve embodied in my sensemaking of the world. Decolonizing my mind helped me understand how my ways of being, knowing, and thinking have been “colonized” and to work within these tensions as my personal process of decolonization (Smith, 2012). For instance, in HIV research, an emerging critique is the use of deficit theorizing: research that promotes deficiencies within peoples of African descent such as the discourse of impoverishment and poverty in sub-Saharan African states. This deficit theorizing too often became dominant ways of viewing Africa and its peoples. In my own research, I started to consider how deficit theorization were derivative of colonial relations and hierarchies of social difference. In these reflections, I considered alternative ways of framing the narratives presented in this thesis, such as troubling the notion of Africa as a single region, offering a historical and sociopolitical context of poverty in certain regions of Africa, or providing varied stories of African women’s socioeconomic realities, not just the ones emblematic of their impoverishment. Moreover, I aimed for strengths-based perspectives that counteracted against analysis of problems such as highlighting resourcefulness of many of the women I interviewed. Decolonizing my mind became a continual, reflective process that encouraged me to interrogate my own research practice which I reflect upon in my methods chapter.

Decolonizing knowing also politicizes knowledge generation. Research addresses topics that attend to the local realities of the communities for which research is conducted (Chilisa, 2012). As I developed my research plan, I considered how my thesis could be action-oriented such as making knowledge sharing to ACB communities a part of my knowledge dissemination plan. I
aimed towards producing knowledge that could be catalytic and praxis-oriented, and that could foster reflective dialogue and critical consciousness.

Increasingly, scholars of African descent have reflected on knowledge generation with, for and by peoples of African descent as decolonizing practices. George Sefa Dei (2015), indicated that methodologies situated in the local cultures and histories of peoples of African descent could help subvert the devaluation of knowledge systems, cultures, histories, and identities. Incorporating knowledges derivative of varied cultural viewpoints within our research promoted its relevance in the academy; moreover, when derivative of the local communities with, for, and by which we conduct research better assured its epistemic saliency and methodological relevance (Dei, 2015). Sotunsa Mobolanle Ebunoluwa (2009) recommended using African women-centred ontology in research for African women. Such an ontological viewpoint should incorporate theories that attend to colonial power relations, respect Africentric worldviews, produce knowledge that challenges dominant discourses and illuminates African descendent women as knowledge producers in their everyday sensemaking of their social world.

Decolonizing knowing can become self and social conscious-raising endeavour for peoples of African descent. Bagele Chilisa and Gabo Ntseane (2010) spoke of the responsibility of African descendant scholars to resist Euro-Western imperialism in our scholarship. Our positioning as “outsider-within” (P. H. Collins, 2000) — racialized scholars within Euro-Western academics — liminally positioned us between two worldviews to reflect upon Euro-Western knowledge imperialism within research (Chilisa & Ntseane, 2010; P. H. Collins, 2000). Notably in the continental African and African diasporic literature, decolonizing knowing emerged as our second sightedness (Du Bois, 1903/2006), or our understanding of the multiple worldviews that shape how we contemplate knowledge generation as members of colonized cultures who are
simultaneously embedded in Euro-Western imperialist or settler states (Dillard, 2012; Hall, 1990). One aspect of this second sightedness is that our outsider-within positioning can be both a source of insight as well as an unresolvable tension. For instance, as I pondered decolonizing the research methodologies that I use, some aspects of producing a thesis were unresolvable such as tensions of ownership where the doctoral academic is expected to claim the knowledge they produce as their scholarship. There remained tensions of responsibility, where accountability to the academy (producing knowledge that has academic credence) may differ from those to the community (generating action-oriented knowledge that has community relevance). The aim is not to resolve all the tensions but to learn from them, and to find ways to chip away at colonial practices that remained in academic knowledge generation. The aim of decolonizing knowledge generation is to *strive to decolonize*: in this striving we move towards decentering Euro-Western imperialism, and creating space for other divergent viewpoints within academic knowledge generation.

So, my approach to decolonizing doctoral knowledge generation within the academy was not solely an epistemic journey, but an existential one as well. Yet, it was in the midst of grappling and troubling methodology and method that I rethought knowledge generation. I considered research methodologies that adhered to the tenets of decolonizing thought: methodologies that employed a relational worldview, attended to power relations within knowledge generation, and honoured the relational accountability of research (Chilisa, 2012; Dillard, 2012; Smith, 2012; Wilson, 2008). Notably, decolonizing knowing using an anti-colonial perspective guided my methodological choices and demanded that they were culturally responsive to the ways in the African women I interviewed knew and related to their social worlds. I selected methodologies that drew upon local worldviews of peoples of African descent, and adapted research methods
that better reflected how the women I interviewed narrativized or made sense of their experiences through story-telling. Lastly, I ensured that research findings were given back to ACB communities as the topic had community relevance. Decolonizing the knowledge generation of Ph.D. research allowed me to be mindful of its ethical and moral stance, a way of being and relating to African women that extended throughout and beyond this research project.

**Transnational Feminist Thoughts**

As I listen to the narratives of the African women that I interviewed, I considered using theories that attended to their experiences as immigrant women who migrated to a Euro-Western settler state. Familiarizing myself with theories from anti-colonial and decolonizing perspectives also directed me to the works of Southern American, Asian and African feminist thinkers whose theorization look beyond Western theories. Instead, their work explored the transnational aspects of the local and its interconnectivity to global relations. The daily working lives of African women living with HIV also interconnected with the global context of HIV and work: working responsibilities of immigrant women in Canada and in their homeland; imaginaries of Canada as a “better life” for people who have migrated from continental African states; and HIV social mobilization that transcended national borders. These transnational feminist bodies of thought altered me to my preconceived understandings of immigration and migration. For instance, I became better acquainted with this notion of “migration” that extended beyond geography: transnational feminist thoughts spoke of the migration of knowledges, economies, cultures, networks, histories and imaginaries that shaped how African women with HIV made sense of their social worlds. Moreover, transnational feminist thoughts offered theoretical perspectives of HIV, employment, and caring work that were under theorized in Canadian HIV research.
Research from a transnational feminist paradigm examines the material, cultural, discursive, and ideological processes and practices through a gender lens (Kaplan & Grewal, 1999). It considers the interconnections between gendered social relations, place and space including the interconnections between gendered processes and practices in relation to local, national, regional or global relations, ideologies, imaginaries, histories, and geographies. Transnational feminism also addresses the differential impact of gendered social relations and how systems of social privilege and oppression shape gender inequities for women, trans* and genderqueer peoples. According to Amrita Basu (2000), transnational feminist thought should think locally, contextualize globally: the unit of analysis occurs at the local level, but interpretations are contextualized within broader social frames (e.g. neoliberalism, globalization and capitalism, patriarchies, nationalisms and citizenship etc.). Analysis is particularly attentive to the (re)production of power through social relations such as how power operates within everyday practices as well as within social constructions of collectivities, subjectivities, and identities (Grewal, 2008). Many transnational feminist thinkers draw from anti-colonial thoughts, interconnecting transnational gender inequities to colonialism. Chandra Talpade Mohanty (2003) among others have examined gender inequities as perpetuating colonial legacies and have interrogated transnational processes of colonial misrecognition, misrepresentation, and maldistribution and their gendered interconnections.

However, I was concerned that in bringing gender to the analytical forefront, other social positionings might be obscured. In the context of my research, HIV brings a particular form of positionality, collectivity, and identity in the context of gender, ethnicity, race, nation, and other social locations. People living with HIV may experience work-related oppressions as sexism, racism, classism, Eurocentrism, or ableism based on the contexts of the denigrated experience.
In HIV-related employment, the desire for employees with formal Canadian credentials can be interpreted as devaluing lived experiences of people living with HIV, Eurocentric privileging of Canadian experience, or the demonstration of classed, gendered, racialized, or nationalized social relations.

I also realized that constructions of place could be integral to how the African women made meaning of their works of caring. Immigrant women’s narrative experiences are often simultaneously situated in multiple locales. In their narrativization, they may re-member the various locales within which they engaged in caring work. For African women living with HIV, they may recall the histories of HIV responses in African contexts in making sense of their caring work as a Canadian AASO employee; they may place-make homeland values of care work within their HIV-related work in Canada; or their positioning as workers could articulate supranational social relations. While transnational feminist theory can aid spatial analysis such as the multiple locales within which African women were engaged and embedded as care workers, the theorization of transnationalism can become grounded in geographic notions of place (K. Brickell & Datta, 2011). This “grounded transnationalism” (p. 3) can leave other constructions of spatiality under theorized such as its constitutions within history, memory, cultural practices, social processes, social networks and social relations. The following theories bring these concerns to the analytical forefront: translocality (S. E. Alvarez, 2014; K. Brickell & Datta, 2011) and intersectionality using translocal perspectives (Anthias, 2008; Yuval-Davis, 2006b, 2007).

**Translocality.** In my conversations with African women living with HIV, I constantly marvelled at the ways in which they sojourned in place: taking me to the places they have travelled within their stories of work. Many scholars of transnationalism have become increasingly interested with the spatial interconnectedness of social practices and processes...
within which migratory human acts are engaged. Transnational theorists have recognized that people's experiences move across multiple local frames of reference, or translocales, when examined across multiple or supra-regional contexts. Drawing upon spatial theory (Agnew, 2005; Massey, 1994), translocality pays particular attention to the social construction of place and space: how places and spaces are constituted in social relations and articulated within social processes and practices (K. Brickell & Datta, 2011). Peter Mandaville (1999), defined translocality as modes of practice from which social actors move through place. His definition recognized movement as everyday practices that express the locales within which human actors are embedded and engaged. Translocality also theorizes the politics of location or how place and space are constituted within power relations (S. E. Alvarez, 2014). While transnationalism primarily focuses on global contexts such as cross-border activities, and transnational interconnections of social activities, translocality focuses first on local contexts — such as the multiple local contexts within which social activities are articulated — before situating it within global frames of reference. Therefore, translocality theorizes global processes — globalized capitalism, migration, transnational networks — as they emerge within local practices.

Central to translocality is placemaking or movement that is “negotiated through multiple articulations of situatedness which constituted the translocal geographies of migrants lives.” (K. Brickell & Datta, 2011, p. 20). Translocality as placemaking, unmoors place from its geographical bounds, recognizing place and space as social constitutions of corporeality and human agency (Greiner & Sakdapolrak, 2013). For African women living with HIV, placemaking emerged within their narrativization of back home, re-membered through story-telling of cultural practices, communion with people from one’s homeland, and homeland histories of activism re-
enacted in Canadian contexts. These locales were territorial as well as ideological, cultural, relational, and psychic.

Notably, placemaking suggests strong temporal elements. Doreen Massey (1994) argued that place can only be recognized as dynamically and processually produced through its temporal connections. As such, narrativized placemaking is articulated within and through time (Massey, 1994). History, memory, and envisioning became central to understanding translocal placement in African women’s narratives. For instance, narratives of back home often interconnected memories of homeland past (i.e., “back home we used to ….”); visions of future work were also tethered to homeland values (i.e., “I expect to become activist here as I was back home”). As such, African women’s narrativization of their working lives became temporal placemaking: narrations of place were anchored in memory, current reflections, or future aspirations.

Placemaking can also articulate social relations within which place is constituted (Basch, Glick Schiller, & Blanc, 1994; Razack, 2007). S. E. Alvarez (2014) noted that translocal social positioning articulated geographies of power, or power relations across social fields (S. E. Alvarez, 2014). Particularly, historical power relations often reflected supranational hierarchies of social difference (Greiner & Sakdapolrak, 2013). African women’s narrativization of work articulated supranational positioning of Western and non-Western states such as the privileged recognition of Western credentials, coupled with the devaluation of non-Western credentials in Canadian labour markets. Theorizing systems of social difference as supranational power relations allowed for critical analysis of colonialism operating in transnational labour markets.

I found Katherine Brickell and Ayona Datta’s (2011) and Sonia Alvarez’s (2014) theorizations of translocality suitable for the Because She Cares study as their approaches distinguished translocality as a process that could emerge through self and social narratives. K.
Brickell and Datta (2011) identified translocales as manifestations of place such as memories of one’s homeland that are remade through narrativization. Notably, in the narratives of African women living with HIV, locales became situated placemaking: experienced in a particular geographic locale (Canada), yet ideological, cultural, relational, psychic and processual articulations of other locales (continental African homelands). Narrativizations of Canada and African homelands also articulated social histories, enacted social values and ideas, performed self- and social identification, and adopted discursive practices of belonging and exclusion. As such, narrativization became placemaking processes.

I primarily use translocality to theorize placemaking in narrativization of work: to decipher the relevance of place and space in African women’s sensemaking of their work in the context of HIV. For instance, I used translocality theorizing to make sense of caring work as articulations of place: geographies of home and settlement lands, spatially located communities, social networks, modes of belonging, and self- and social positionings. Attentiveness to placemaking as a social construction also allowed me to question social narratives of place such as how African women living with HIV made sense of back home, Africa, and Canada. Furthermore, translocal theorizing allowed me to interrogate time and place in narratives of work such as the use of memories and imaginaries of one locale to make sense of work in another local context (i.e., comparing one’s work in Canada to back home). Lastly, translocal theorizing offered a way to bridge the local experiences of work to global processes of migration, globalized capitalism, transnational labour markets and transnational care. Thus, in theorizing translocality, I did not just explore the geographic places within which African women are located, I uncovered how place was enacted, performed and articulated through women's narrativization of work.
Translocal Intersectionality. In my conversations with African women living with HIV, I became saliently aware of the multiple forms of social difference, privilege and oppression they navigate as racialized women immigrants living with a stigmatized health condition in Euro-Western settler spaces. I have noticed how their responsibilities as women workers shifted across context such as transnational social relations (i.e., primary or sole breadwinner in Canada, while secondary or co-income earner in one’s homeland) yet gendered relations still operate in how their work is regarded (i.e., expected to be primary caregiver along with other work responsibilities). I also understood that local gendered relations as transnationally raced and classed such as supranational income inequities coupled with care deficits resulting in the overrepresentation of immigrant women as transnational care labourers (Pyle, 2006).

Sonia E. Alvarez (2014) recommended that interpretation of intersecting systems of privilege and oppression across transnational social fields should recognize immigrant women as "translocated subjects". This translocated understanding considers social constructions of differentiation (i.e., gender, ethnicity race, class and nation among others) their constitutions within multiple social systems (i.e., capitalism, colonialism) within local and across transnational social fields and that these constitutions are both distinct to local contexts and intertwined amongst them (S. E. Alvarez, 2014). So, I desired to use theories that helped me understand how these multiple forms of social differentiation are narrativized within African women’s stories of work.

Intersectionality examines intersecting systems of social difference along axes of power, privilege and oppression (Crenshaw, 1991). Power and oppression are embedded within the social structures within which African women are engaged, are articulated within their relations with others, and embodied within their ways of being in and sensemaking of their social worlds.
Intersectionality as an analytical lens can deconstruct how power operates within social relations, institutions and organization, as well as through discursive practices such as self- and social narratives (P. H. Collins, 2000). More recent thinking around intersectionality considered social location as mutually constituted and differentiated by the locales to which people are socially positioned (Anthias, 2008; Yuval-Davis, 2007). Floya Anthias (2008) and Nira Yuval-Davis (2006b, 2007) theorization of intersectionality examined how constructions of differentiation cross local contexts. This examination allowed for an analysis of systems of privilege and oppression in local and transnational contexts as it interconnected to constructs of differentiation such as race, gender, nativity, immigration status and HIV status. I primarily use translocal intersectionality to interpret mechanisms of oppression and identity formation narrativized in African women work narratives as they were situated within local contexts and across transnational social fields.

A translocal intersectionality lens also recognized how agential performances move across translocal contexts, such as ways in which women who are engaged and embedded in multiple locales, which may have varied and interconnected gendered relations, can question, challenge, and re-imagine gendered performatives of work. While intersectionality is commonly taken up to interpret mechanisms of oppression, it also can been used to understand identity formation, including agential positionings shaped by systems of social differentiation (Anthias, 2008).

Particular to the Because She Cares study was the understanding of intersecting positionings — gender, race, ethnicity, nativity and HIV-status among others — as foundational to reclamation, conscious-raising and mobilization. Interpreting intersectional consciousness, or a conscious self and social positioning across multiple intersecting sites of social differentiation can help explain why people may identify with multiple marginalized identities, seeing them as sources of power-
within (agency, self-consciousness) or power-with (collective empowerment, identity consciousness). Such oppositional consciousness is commonly found in activism, where people will transform marginalized social positionings into an empowered identities (Mansbridge, 2001). While agent positionings do not mitigate the broader power relations of intersecting systems of oppression, an intersectional analysis can help interpret how agential positionings can be constitutive of power relations while still aiming to resist or transform them.

My approach to translocal intersectionality analysis considered the geographies of power that operate within the locales within which African women living with HIV are embedded and engaged. Consequently, this translocal intersectional analysis was transnational in scope as it deciphered power relations as they dynamically and fluidly operated across local contexts, as well as the broader social forces at play. This analysis interconnected broader frames of reference (i.e., globalized colonization), including transnational systems of privilege and oppression and the historical and contemporary context of these systems (i.e., colonized systems of privilege, and oppression reified within HIV-related work). As such, translocal theorizing aided my examination of systems of social difference within different locales, and how they interconnect and mutually inform each other.

I selected transnational feminist thoughts such as translocality and translocal intersectionality to ensure that I was better able to understand caring work from the translocated eye of my African woman colleague; I wanted to ensure that the sensemaking of caring work, through time and place, would not get lost as I made sense of African women’s HIV-related work as caring work. I also wanted to assure that the colonial perspective was not lost either. As such, I chose transnational feminist theories that complement my decolonizing, anti-colonial perspective. Translocal theorizing illuminated the politics of placemaking, such as the gendered geographies
of power11 and the social systems — patriarchal, institutional, neoliberal, geopolitical, colonial - within which spaces and places were constituted (S. E. Alvarez, 2014). Translocal intersectionality aided my analytical unpacking of the varied and particularized ways in which imperialism and colonialism can manifest and their representation as intersecting systems of racialization, racism, Eurocentrism, xenophobia, classism, class privilege, sexism, and patriarchy among others. I also favoured intersectionality theories developed by transnational feminist thinkers to best ensure that my intersectionality analysis incorporated systems of social differentiation, privilege and oppression across local and transnational contexts. While intersectional analysis denotes intersecting matrices of power, privilege and oppression, translocal intersectional analysis focuses on their varied spatial articulations. So, in choosing transnational feminist theories, I better assured that my interpretations moved away from the Western eye, to a lens more congruent with African women’s sensemaking of their HIV-related work, as caring work.

The Personal in The Theoretical: Positioning Myself as a Decolonizing, Anti-colonial Transnational Feminist Thinker

I recognize I may position myself more overtly within my doctoral writing than what is expected, which is not to say that this is novel. In many ways, we all position ourselves through our theoretical choices and our integration of them within methodology and methods. Our epistemological stances are an intellectual exercise as well as a personal endeavour; as we choose

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11 S.E. S. E. Alvarez (2014) understanding of geographies of power echoed that of Patricia R. Pessar & Sarah J. Mahler. *Gendered geographies of power,* (Mahler & Pessar, 2003) is a conceptual framework for examining gender in the context of transnational migration. This framework conceptualizes the multiple places and spaces within which gender is constructed (geographic scale), the multidimensionality of social positioning at local, social, national and transnational levels (social location), and the type and level of agency within which people can exert agential or collective power over their social conditions (power geometry). While Pessar & Mahler developed this framework for gendered analysis of transnational migration, Alvarez’s understanding of geographies of power recognizes “geographies” and “migratory” as processual and relational.
theories that guide our research, we often reveal who we are. As Sean Wilson (2013) suggested, the theories we choose for our epistemological framework are founded on our belief systems which consequently shape our understandings of knowledge and knowing, substantive areas of investigation, strategies for inquiry, and inquiry methods. I also believe that the theories we choose reveal our ways of being with knowledge, including what we believe knowledge generations can do: test a notion of reality, contextualize a social construction of reality, (de)construct a dominant notion of reality, or reframe alternatives.

As a person of African descent, I admit it was easier for me to choose anti-colonial and decolonizing theories for the Because She Cares study because these theories allowed me to better understand my place as a knowledge generator, within and outside the academy. As a Western-born and educated academic, however, my choice of transnational feminism initially seemed less “personal”: the transnational feminist epistemes seemed initially about the women I interviewed. As I familiarized myself with transnational feminist thoughts, I realized my gravitation to these epistemes were personal as well. I wanted to find theories that helped me learn from the women I interviewed.

Chandra Talpade Mohanty (1988) challenged researchers to avoid using a myopic Western lens when understanding the experiences of transnational lives. I heeded her warning and chose transnational theories, so I could better understand how the narrators made sense of their HIV-related work as immigrants, peoples of African descent, and workers within multiple locales. Yet, as I conducted this research, I became more conscious of my belonging and positioning that was shaped by ancestral histories, stories of my parents homeland, memories of my parents migration experience, and my experiences of being positioned as not from “here”. Using this translocal consciousness, I made sense of experiences of immigrant women of African descent as a
Global “Northerner” who has been raised and reared in a Western culture, but also as a Global “Southerner” who histories, genealogies, legacies and understanding of my “place” in the world also derive from the Global South. As a second-generation Canadian of Afro-Caribbean heritage. I made sense of the Narrators’ stories as a person who is geographically located and socially acculturated to Canadian Euro-Western space, and as a child of Caribbean immigrants who was acculturated to Caribbean values and practices, and socially positioned in Canada as a “newcomer” who is not from here. My translocated genealogies, histories, social networks, cultural practices, senses of belonging and geographical placements as a second-generation Canadian of Afro-Caribbean heritage influenced my topical, methodological and interpretive choices. My translocal consciousness of seeing and viewing the world acknowledged the pitfalls of a Western myopic viewpoint, so I used transnational theories to make sense of them. I also maintain that the stories of the women I interview who are also women of African descent, are not OUR stories, though they may personally resonate with my experiences of working in the HIV sector as a person of African descent. This translocal consciousness — a consciousness of the transnational and how it can be remade in the local — made me aware of my positioning in relation to the women I interview, and vice-versa; though we may share ancestral histories and racial commonalities, geographies of power, varied experiences of colonization and differential intersecting systems of power, privilege and oppression shaped how we identify or were identified as peoples of African descent.

This translocal consciousness also draws from decolonizing knowing perspectives. My colleague Randy Jackson, an Anishinaabe scholar, taught me the Indigenous principles of two-
eyed seeing\textsuperscript{12} which speaks to the process of seeing the world using the strengths of both Western and Indigenous viewpoints (Jackson, 2012). In sharing this concept with me, he emphasized its parallel to Dubonian notion of second sightedness, grappling with viewing the world from both Euro-Western and Africentric viewpoints and gaining insights from this struggle (Du Bois, 1903/2006). This second sightedness of which Du Bois and Jackson spoke made me more conscious of balancing Western and local knowledges within my doctoral research, and how to design a doctoral research study that drew upon ways of knowing not as familiar in the academy, yet still met the standards of a Ph.D. While there remained tension in using this translocated second sightedness within Western context, in recognizing the strengths of different ways of knowing, it can offer insights that one perspective alone may not attain (Jackson, 2012).

Applying decolonizing, anti-colonial perspectives of transnational feminist thoughts familiarized me with theories that contextualized African women’s experiences in the context of HIV and work and unearthed their unjust or oppressive underpinnings. It also encouraged me to apply strength-based approaches that illuminated resilience and resistance that emerge in African women’s stories. Moreover, this framework alerted me to research methods that were situated in ways in which the African women I interviewed made meaning of their experiences. These theories also alerted me to how I was making sense of African women’s experiences from my translocated eyes. So yes, the theories I have chosen for my epistemological framework are personal: they are reflective of the belief systems which I bring to my understandings of HIV,

\textsuperscript{12} The Indigenous concept \textit{two eye seeing} originated from Mi’kmaq Elders Murdena and Albert Marshall from Eskasoni First Nation, along with Dr. Cheryl Bartlett at Cape Breton University’s Institute for Integrative Science and Health/Toqwa’tu’kl Kijitaqnn (Iwama, Marshall, Marshall, & Bartlett, 2009). Elder Marshall expresses two eyed seeing as: "...to see from one eye with the strengths of Indigenous ways of knowing, and to see from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together" (Bartlett, Marshall, & Marshall, p. 335).
work, and knowledge generation. I believe that academic knowledge generation should bring forth diverse viewpoints rather than continually reproduce the status quo; utilize methods that are culturally responsive to the ways in which participants know their social world; trouble dominant constructions that uphold oppressive viewpoints; and grapple with difficult questions, including how we can create more space for knowing practices not commonly utilized in academic scholarship but relevant for the communities with which we work. And I believe that we all conduct research that is personal: the theories we incorporate in our theoretical constructs often reveals who we are as knowers, and what we think knowledge and knowledge generation can do.
Chapter 4: Knowing Practices (Methodology): Performance Narrative Inquiry

In my troubling of methodology and method in the academy, and in my grappling with how to approach the Because She Cares study using decolonizing, anti-colonial and transnational feminist standpoints, I decided that my relational regard could serve as a knowing space. I considered how I could I draw wisdom from others engaged in HIV research who, like me, desired research methodologies that are culturally responsive to the communities for and with which we work. And who better to assist me in developing methods that responded to the ways in which African women may know their social world, then women who desired the same. So, I started conversing with people engaged in HIV research to collectively reflect on research methodologies with, for and by women of African descent. These dialogues became a pilot research project that was a requirement for my doctoral coursework, wherein the Fall of 2014, I consulted six community advocates — women with HIV-related research experience who also identified as women of African descent. In our conversations, we discussed their experiences with HIV qualitative research: the concerns they had with such research and their recommendations for culturally responsive research. This pilot study was rooted in the African Indigenous philosophy of sagacity, where the wisdom and expertise of those with experiential know-how were integrated into the research design and practice (Chilisa, 2012; Oseghare, 1992).

What these conversations with other knowers of African descent illuminated were our shared desires to use research methodologies that were reflective of the ways in which we make sense of our social worlds. The community advocates I interviewed critiqued research where they could not see research participants as knowledge generators. They were also critical of knowledge dissemination forums — academic conferences and peer-reviewed journal articles for instance — not designed for community audience and which used language that was difficult for
them to decipher. They wanted research to be communicated in ways that were accessible and understandable to them; they recommended approaches that engaged community in the knowledge exchange rather than talked down to them; and they recommended venues such as community forum where community members could dialogue with the researcher. Although the community advocates I interviewed came from various countries, there were some commonalities in the knowing practices they favoured: preferences for performance and narrative knowing practices such as oral narrative, storytelling, photovoice, and the dramatic arts. They also endorsed knowledge generative approaches that could make research more accessible to the masses such as arts-informed practices (i.e., drama, song, theatre, poetry, parables, and visual arts). The culturally responsive approaches they recommended illustrated the multiple ways in which women of African descent could know and relate their wisdom: dialogically, reflexively, creatively, emotionally, sensuously, and spiritually.

While their advice guided me towards performance narrative methodologies, I struggled with doing it. Part of this was the struggle for legitimacy as scholar of African descent who is translocally conscious. While Canadian Schools of Social Work continue to push for the representation of marginalized social groups within the academy, I still sensed that few in my school understood what it meant to be a racialized scholar of African descent whose racial group is too often marginalized in educational systems (Dei, 2014). As I met with other scholars of African descent in Schools of Social Work, I realized that despite our differential identifications with being “Black”, we had similar experiences of being “blackened”. For instance, many of us struggled with being scholars from the margins, as there seemed to be an expectation that we “represent” our “communities”. One thing I struggled with was mis-representation, for instance the stereotypical representation of scholars of African descent as “emotional” (“angry Black
women”) or “artistic”. (“They can dance!” “They can sing!”). I recognized that these struggles with mis-representation were indicative of colonization: these racialized stereotypes were othering processes that shaped how I may be perceived in the academe (Chilisa & Ntseane, 2010). In this struggle of mis-representation, scholars of African descent may shy away from culturally responsive methods that position such knowledge practices (and its practitioners) as the other, or as less rigorous, less scholarly because it does not derive from the Euro-Western ontologies legitimized in academic scholarship. In my case, I feared that people would interpret my methodological approach as *folklorism* (Madison, 2008; Madison & Hamera, 2006), a romanticizing of culturally responsive methodologies that did not recognize their methodological soundness. And so, I worried. I worried that these stereotypical mis-representations of peoples of African descent signified how knowledge generation from Africentric precepts may be viewed: as entertainment but not as scholarship.

And yet, as I pursued my Ph.D., I questioned the legitimacy of me not pursuing culturally responsive methodologies that drew from the local knowledges of peoples of African descent. I also wonder if this notion of “culturally responsive” required me to consider the local knowledges that shape how I know. I come from a family of storytellers: the learning of my social world derived from the narrative practices of my family. Common to my Jamaican culture, social knowledge is often debated, counter-storied and restored through poetic and literary arts, and performed within theatre, music, and oratory. As a young adult, I had gravitated towards the performance arts using oral storytelling, creative writing and poetry to reflect upon my social world as well as to relay knowledge to others. As a young knower, I used to know through narrative, poetry and performance. I used to … but why couldn’t I continue to? Why couldn't
the ways in which peoples of African descent know outside of the academe feature in the knowing practices we use in research?

In engaging in this struggle alone, I assumed that these methodological choices were mine to make. That I was the omnipresent methodological expert, and that the women for whom this research was with and for should not factor into this decision making. However, as I allowed myself to discern their understanding of HIV-related work as caring work, I also learned how they transmitted this knowledge. Through narrative performance. Kissing teeth. Slapping tables. Shaking their hands. Nodding their head. Yelling. Laughing. Singing. Crying. Sighing. Pausing. Thinking. Reflecting. Being expressive. Being emotional. Being thoughtful. Being intellectual. They produced knowledge through their performance of what they knew. Once again, it was sagacity of women of African descent who guided my knowing practices. This time, it was the women I interviewed who challenged me to know artfully with narrative performance: to engage my artistic and intuitive sensibilities in recognizing oral narrative as poetic performances (Knowles & Promislow, 2008; Sinding & Barnes, 2015).

My move to knowing artfully, or in the context of this research, knowing through arts-based narrative performance, did not initially come from a theoretical grounding of the arts-informed literature. I was provoked in doing so through dialogic engagement with the African women I interviewed. As study participants, whom I call the Narrators, shared their stories with me, I became attentive to HOW they were telling me their story. Their narrative oration was as informative to their sensemaking as the story told. Also, the emotive and embodied ways of knowing my social world invited me to interpret and represent their narratives in that manner. Through this knowing, I found poetry as a methodological practice.

I FOUND POETRY within the women’s stories.
The first poetic finding occurred in my second interview. To illustrate her experiences of working in community activism back home, the Narrator I interviewed sang a song to me. The first verse, she sang in her local language; the second verse, the English translation. I was not only moved by what she sang but how she performed the joys of HIV-related work through singing this song. This song represented both a narrated and narrative experience (Bruner, 1990): a narrative of her HIV-related work back home (narrated experience), and the experience in which both of us — her as the orator and singer, me as the audience, us as co-knowers — engaged at that moment of the telling (narrative experience). Furthermore, my immersion within the narrative experience — listening to the oral narrative, experiencing its oratory — illuminated the sensory, emotive and embodied nature of the knowledge I gathered. In writing my field notes, I identified potential themes related to this song, and how this song made me feel. This experience alerted me to the different ways in which the second Narrator I interviewed talked about her work back home compared to her work in Canada, and how this song was representative of these contrasts.

Taking these methodological insights discovered from my second interview, I revisited the first. As I re-listened to the audio recording, I distinguished how the Narrator narrativized her experiences of work, not just the words she said but how she expressed them. When I transcribed her interview, I noted non-verbal communication — pauses, vocal tone, inflection, rhythm, emotional expression and body language — and made notations within the transcript. In revising my transcription, I could also see that the narrative had a lyrical quality. Sentences became line breaks, changes in vocal tone were textually emphasized using capitalization, italics, bolding, underlining and verbal notations. Using textual notations and stylization, the oral features of the narrative experience emerged.
As these first two interviews alerted me to the performance aspects of oratory as a narrative experience, I started to adapt my methods to reflect this. I was more attentive to indicating paralinguistic (e.g., pitch, volume tone), proxemics (e.g., interpersonal interaction, use of space), and kinetic communication (e.g., body language) during the interviews and reflected this in my field and reflective notes. I would repeatedly listen to interviews to get a feel for oral narrativization. In this repeated listening, I became alert to how the Narrators’ stories of HIV and work resonated for me as an audience: they stirred emotions, made me think about HIV-related work differently or implored me to share this passage with others. For me, this resonance seemed best evoked through the poetic arts; using poetic orchestration — arrangements of narratives into lines and stanzas, textual formatting and punctuation to illustrate emphasis and lyricism — to highlight what resonated such as arguments, tensions, and emotions (Kearney, 2015). I adapted my research methods to feature the varied communicative qualities of oral narrative and the lyrical fashion of the Narrators’ oratory.

For me, these stories were poetic.

My background in storytelling and poetry may have fostered an alertness to the aesthetic and rhythmic qualities of oral narrative, but these qualities were also coming from the Narrators themselves. As I listened for narrative performance in subsequence interviews, I became more alert to the poetic qualities of oral narratives and how it could generate cognitive, emotive and reflexive meaning for the audience. I also became attentive to how I — as inquirer and as audience member — was drawn into these stories: as a person of African descent, of Caribbean heritage, who is HIV-negative, and works in HIV-related work.

While found poems has been defined as a methodological approach of transcribing, interpreting, and representing narrative research data as poems (Hordyk, Ben Soltane, & Hanley,
I found this definition did not convey what I was finding — I was finding how my ways of knowing and being in the world allowed me to find poems within narrative data in the first place. For me, finding poems was a relational practice, a respectful practice, a moral practice, a culturally responsive practice, a personal healing practice AND a knowing practice. Finding poems in participants’ narratives encouraged me to listen deeply to them, represent them in a fashion that represented their narrative sensemaking of HIV and work, and offer research methods that responded to the ways many women of African descent from oral narrative cultures know their social world.

In discovering other researchers who also found poetry in their research work, I became attentive to the moral and emotive imperative to find poems in my research. Cynthia Poindexter (2002) turned some of the quoted passages from her doctoral research study into poems. Her intent was both aesthetic and empathetic: to offer the emotional resonance of oral narrative more succinctly, and to bring forth the narrative experience through poetic re-presentation (Poindexter, 2002). Poetic interpretation allowed her to reconnect with the experience of the original telling, and to share that connection with readers through poetry. Corrine Glesne (1997) in her longing to bring forth her creative voice, turned to poetry-writing at the same time she was conducting a life story narrative research project. Though she had not planned to incorporate poetry into her research, she felt compelled to do so. Incorporating poetic vignettes in her life story research blurred the boundaries between the humanities and social sciences, more in keeping with her ways of knowing the world.

In both examples, finding poetry was not only an alertness to the poetic nature of oral narrative speech, it also responded to the evocation of interpreting and representing research poetically. For Poindexter, poetic methods were a moral evocation, to better assure that her
presentation of participants’ narratives were more representative of the narrative and narrated experience. For Glesne, poetic methods were an embodied evocation, to respond to her longings for a creative outlet in her academic work. And in reading Poindexter and Glesne discuss how they found poetry in their narrative research work, I became aware that I was not only finding poems through the evocative qualities of speech, I was also discovering how the Narrators’ ways of narrativization were illustrative of how I story-tell as well.

I also found poetry as a narrative methodology through “bearing witness” to the Narrators’ stories. According to Lillian Comas-Díaz (2000), bearing witness could facilitate decolonizing knowing as it considered how one’s personal story could have catalytical impact. In bearing witness, I became acutely aware of what these stories could do if retold in a manner that brought forth what I was experiencing. If I was emotively responding to these stories as I gathered, and re-listened to them, couldn’t other people respond to them in a similar manner?

In reading other writers who theorized knowing poetically, I was reminded of the cultural place of poetry in many continental African and African diasporic cultures. In Caribbean cultures, poetry has served as politicized practices that re-write/re-right Caribbean histories too often omitted from Euro-Western texts (Gilroy, 1993). Caribbean poetry has also been used to reaffirm our ways of knowing — locals idioms, and colloquial languages — within Western literature (Condé & Lonsdale, 1999). For Ngūgī wa Thiong'o (1986), a Kenyan writer, poetry in African cultures derived from the oratory of African languages; poetry as an expressive art also became “a language in itself with its own structures of beats, metres, rhymes, half-rhymes, internal rhymes, lines and images” (wa Thiong'o, 1986, p. 87). Audre Lorde (1984) spoke of poetry as consciousness for peoples of African descent, a way to reconnect to the ways in which they knew prior to colonization. These understandings of poetry as local knowing practices were
congruent with Dei’s theorization of the trialectic space, where knowing moved beyond the rational mind, to encompass body, soul and spirit; interfaced with history, and its legacies; recognizes the sacredness of local knowing practices; and connected to cultures precepts and practices (Dei, 2012b). In essence, finding poems was a way to honour OUR — the Narrators and my own — ways of knowing. Representing the Narrators sensemaking in poetic form could evoke the sensory, emotional and embodied nature of the narrative experience; using research methods that are culturally responsive to the ways in which WE — the Narrators and I — knew could promote poetry as an academic knowing practice in the social sciences.

Thus, these poetic findings implored me to heed the aesthetic, poetic, personal, political and epistemic calls to artful knowing through poetic performance. Instead of shying away from knowing practices that are not as commonly used in the academy, I allowed myself to find methods that were illustrative of the Narrators’ sensemaking of their social world. I also found it fruitful to draw from my ways of knowing the social world, as they allowed me to methodologically respond to participants’ ways of knowing as well.

**Performance Narrative Methodologies**

My poetic approach to narrative transcription, interpretation, and representation draws from performance narrative methodologies. Performance narrative methodologies involve gathering, interpreting, and sharing textual, oral, or visual narrative data — oral stories, memoirs, letters, photos, and video diaries for example — while recognizing its storied form. It distinguishes *narrative as a social resource and as a social practice* (Squire, 2013). As a resource, the narrated account becomes a source of data. As a practice, the process of telling a story — context, audience involvement, and communicative aspects — also becomes part of the interpretation. Performance narrative methodologies consider story-telling a form of sensemaking and treats
narratives of personal experience as a reflexive and consciousness raising act that exist as their own knowing practices (Madison, 2008). Meaning is made through re-membering: recalling memories of past experiences so that they have resonance in the present, and using memories and one’s sensemaking of it as a resource for envisioning the future (Plummer, 2001). This understanding of re-membering recognizes that memory is dynamic, perspectival, subjective, and contextually contingent as one’s sensemaking of the past is reshaped by present-day experiences. Performance narrative is particularly interested in the social relations of communicative acts. Social narratives serve as a resource in which to make sense of human experiences and to discern social processes such as social positioning, identity formation, and belonging (C. Brickell, 2003). Narrative performance as constitutive, expressible, creative and conscious-raising grounds my choice of these performance narrative methodologies: performance narrative inquiry and poetic narrative inquiry. The complexities of narrative sensemaking as agential and performative practices make performance narrative methodologies well suited for exploring the narrative experiences of African women living with HIV who are employed in HIV-related work.

Local and transnational HIV responses have a long history of using narrative performance of people living with HIV. For instance, the personal narratives of people living with HIV have been used to trouble dominant constructions of HIV subjectivities (Bourgault, 2003; Lather & Smithies, 1997; Rudd & Taylor, 1992). Their personal stories have served to disrupt misinterpretations of HIV seropositivity (i.e., HIV and AIDS as being synonymous with death) and denaturalize perceptions of people living with HIV (i.e., reflecting their cultural and social diversity). The performance of personal stories can counter moralized HIV identities and the dehumanizing process of HIV-related oppressions and discrimination.
Yet, as personal stories get leveraged to further the political narrative of HIV, they, in turn, have become naturalized narratives of the response. Story-telling in this vein became “talking technologies” (Mazanderani & Paparini, 2015, p. 71), where telling one’s personal story served as self-regulating practices that governed how one should perform their seropositivity. The coming out story, for instance, disclosing one’s status publically to combat HIV-related oppressions, has become intrinsically tied to work involvement in HIV responses or peer engagement as empowerment. However, this social performance of HIV peerhood does not recognize the complexities of disclosure for many people living with HIV, including immigrant women of African descent who may be selectively open within their communities or their families. In this vein, HIV story-telling becomes a performative tactic that mimetically recites idealized social narrative of living with HIV such as how one should identify with HIV or disclose their seropositivity. HIV story-telling can also recite social performatives and power relations. The political performance of race, gender, national and HIV identities can reframe subjectivities as well as name their racialized, gendered, colonial, and moralized origins.

I chose to use performance narrative inquiry and poetic narrative inquiry to highlight the performance of the narrative act and to decipher how narrative sensemaking can illuminate social performatives and agential performances as they emerge from the narrated experience. I also found that both approaches were culturally responsive to the ways the Narrators were making sense of their experiences of HIV-related work. To situate my methodological approach, I used the theoretical literature on performance theory and poetic performance. As performance and narrative has a strong history within decolonizing, anti-colonial, and transnational feminist thoughts, I also looked to this literature to better understand how performance narrative can compliment decolonizing knowing as anti-colonial and transnational feminist praxis. Since poetic
interpretation and representation became a component of my methodologies, I also looked to
the literature on poetry and performance to decipher what I was “finding” in oral narrative
performance.

**Performance theory and performance narrative inquiry.** Performance theory draws
heavily from critical cultural theorists such as Judith Butler (1993, 1999) and Dwight
Conquergood (1986, 1998, 2002) who recognized the corporeality and human agency of social
performance. Judith Butler recognized the socially constitutive nature of discourse, where
human actors embody and express social norms, values, mores and expectations through
discursive acts such as narrative communication. *Performativity* — culturally sustained rituals that
become embodied through repetition (Butler, 1999) — are realized through discursive acts such
as self- and social narratives. The power of narrative is “to reproduce effects through
reiteration” (Butler, 1993, p. 20). Social norms become embodied through our social
performance (Salih, 2007). Discursive acts such as narrativization is one strategy of articulating
this embodiment.

While Butler illustrated the performative nature of personal narratives, other performance
theorists emphasized the malleability of social performatives. For instance, performance
theorists, drawing from Victor Turner’s (1982) work, noted the role of performance in troubling
and remaking social performatives. Turner understood social performance as *poiesis*, of remaking
culture rather than solely reproducing it (Madison & Hamera, 2006). For Turner, performances
served as a vehicle for individual or collective reflexivity. Performance existed in this liminal
space between what is expected (social norms) and what could be (self- and social innovation)
(Turner, 1982). Performance allows one’s social world to become the object of observation and
reflection, for the individual as well for the audience of the narrative experience. Performing
narratives therefore serve as a mechanism of reflexive activity, where understanding emerges through the act of the telling and witnessing. Thus, Turner tasks narrative performance with achieving poiesis: to remake meaning of an experience or event through narrativization such that it makes sense to the audience, or to generate reflectivity that can lead to self or critical consciousness.

Performance theorists drew upon Turner’s theories of poiesis to theorize performance as *kinesis* or social movement. Kinetic performance undertakes provocation: to evoke emotions, shift minds, raise consciousness and promote action. Dwight Conquergood theorized performance as a tactic of reinvention that positioned human actors as agents of transformation (Conquergood, 1995). Thus, narrative performance is potentially transgressive or political as it “emphasizes performer creativity to ground possibilities for action, agency, and resistance in the liminality of performance as it suspends, questions, plays with, and transforms social and cultural norms.” (Langellier & Peterson, 2006, p. 155).

Performance as decolonizing knowing, anti-colonial thought, and transnational feminist praxis harnesses the kinetic nature of narrative performance to deconstruct, disrupt and shift ways of thinking. Additionally, it recognizes the responsibility of narrative inquirers to integrate the provocative nature of performance in their research, for instance integrating performance arts such as poetry or theatrical performance within knowledge gathering, interpretation, or mobilization. Transnational cultural artists and theorists have considered performance a “culture of resistance” (Gilroy, 1993, p. 37): a social practice of troubling, subverting, resisting or transforming cultural norms or creating a counter-culture where politics are dance, acted, sung or played out. For socially disenfranchised groups, performance has historically been a tactical tool to disrupt and trouble dominant discourses or break and remake dominant performatives.
There also remained the decolonizing potential of performance — to resist cultural erasure, reclaim cultural expression, challenge imperialist discourse, transform one’s marginality, heal colonial wounds — upon which many colonized cultures draw (Dillard, 2012). Within decolonizing, anti-colonial, and transnational feminist thoughts, performance narrative inquiry can become critical practice, using knowledge gathering, interpreting and sharing methods that trouble preconceived notions of data collection, analysis and dissemination, or reclaim local practices of knowledge generation.

**Poetic narrative inquiry as performance narrative inquiry.** Performance narrative methodologies are not just an interpretative knowing practice but a representative one as well. Performance narrative represented as poetry strives to capture what stories do through narrative performance, particularly how meaning is made through the telling of the experience (Madison, 2008). Representing oral narratives as poetry evokes other aspects of human sensemaking that words alone cannot capture such as emphatic, emotive and bodily expression. Poetic representation can also become an interpretive process that emotionally connects the inquirer to the narrative experience. As such, poetic narrative inquiry engages mental, sensory, and embodied processes of inquiry that can allow a deeper, reflective understanding of the narrated and narrative experience.

Notably, poetic representation within academic scholarship can become a provocative act. For instance, poetic representation within social science research offers alternative modes of knowledge representation. While prose is the common representation practice of academic scholarship, performance narrative inquirers recognized that people rarely speak in prose. Instead, oral narratives tend to be poetic rather than prosaic. And yet, Dwight Conquergood (2002) suggested that academic knowers commonly embraced prosaic representation because it
represented the communicative acts of high cultures, or the elite or educated classes. Yet this bias for academic prosaic representation allows academic scholarship to potentially be inaccessible to non-academic audiences.

Derrida (1988) suggested that communication is not innocent: the words that we use, the genres we select, the audience to whom we write operated within a discursive frame of social values and power relations. Consequently, prosaic social science writing performs socially privileged discourse; it offers knowledge generation as selective, esoteric, and unattainable to masses, a privileged way of knowing that is revered in our society. Leggo (2008) offers poetry as a non-linear representation of knowledge that can resist knowledge hierarchies of cerebral versus emotional knowing and can disrupt the empirical dualism of art-science, mind-body, self-other, researcher-participant, interpreter-audience that often emerges within academic writing. Notably, taking an approach to poetic representation that is illustrative of sociolinguistics (Gee, 1985), or poetic aspects of everyday speech (Madison, 2008) can produce more attainable knowledge for lay audiences.

As such, I decided to incorporate poetic narrative inquiry within my methodological approach. Poetry as narrative performance responds to the oral narrative expression in many continental African and African diasporic cultures. It disrupts the common representation of “participants” in research; instead it positions the Narrators as co-knowers or co-producers of knowledge, fore-fronting them as originating transmitters of knowledge from which my interpretations derive. I also envisioned poetry as a knowledge sharing vehicle, using performance activities (e.g., spoken word performances of poetic retelling) to translate knowledge on HIV, work, and caring labour deriving from this thesis. This positioning of narrative performance as culturally responsive and politicized knowledge generation is consistent
with a decolonizing, anti-colonial and transnational feminist framework. I aimed to position the narrative performance of the Narrators in the forefront, and generated knowledge that transgresses dominant notions of academic knowledge generation.

My approach to poetic narrative inquiry privileges women theorists from continental Africa and the African diaspora who drew from their own cultural knowing standpoints; they served as my ontological and epistemological sages, offering examples of narrative knowing that were congruent with decolonizing, anti-colonial, and transnational feminist thoughts. I was also guided by transnational scholars who incorporated creative expression in their intellectual work such as Audre Lorde (1997), Gloria Anzaldúa (1987), Chimamanda Ngozi Adichie (2009), Dionne Brand (2001), and other transnational poets (Patke, 2006).

**Decolonizing, anti-colonial, transnational feminist thoughts and performance narrative inquiry.** Decolonizing, anti-colonial and transnational thinkers have argued for racialized scholars to use methodologies that revel in the ways in which they know outside of the academy, as both a critique of the power relations of knowledge generation and as a self-reflexive practice. Poetry as an interpretive and representation practice has commonly featured in the scholarship of decolonizing, anti-colonial and transnational thinkers because of its evocative and provocative potential. Ngugi wa Thiong’o (1986) proposed that in our efforts to decolonize our minds, transnational thinkers should harken back to ways in which we know. For Thiong’o, this included the use of orature and poetry in our scholarship since it has a history and longevity that precedes and succeeds colonization. Audre Lorde (1984) offered poetry as the source of theorization, a “revelatory distillation of experience” (p. 37). For Lorde, poetry is a sensemaking practice that germinated reflective thought. Cynthia Dillard (2000) recommended that racialized feminist scholars respond to their yearning for methodological tools of their own;
poetry derivative of local practices such as oral narrative can reclaim local knowing practices in academic knowledge generation. Anzaldúa (1981) implored racialized scholars to resist the “white-right” where to be heard as academics, to BE SEEN as academics, one must assimilate to the dominant discursive strategies used in the academy. As such, using methodologies derivative of one’s own cultural standpoints can offer an academic “voice” that transgresses the dominant Euro-Western standpoint. Decolonizing, anti-colonial and transnational feminist thinkers implored racialized women to use the ways in which they know as a source of reflection and resistance to Euro-Western discursive dominance.

I also choose performance narrative methods that were complementary to translocality theories. Narrative methodologies that incorporate life story-telling encourage translocal journeying. People often use oratory performance, telling a narrative experience to an audience, to re-member past experiences such that they resonate for the audience. This re-membering can become translocated placemaking, articulating time and place through narrative (K. Brickell & Datta, 2011). Translocal placemaking also engenders reflection: the reflexive process of narrativizing experience often occurs across time-space scales. Translocal journeying and re-membering place is common in immigrant story-telling, where oral narrative becomes cultural practices of knowledge transference or sharing homeland histories, memories, and knowledges to significant others to assure its continuance within homeland communities (Chilisa, 2012). Translocal journeying and re-membering place can bring back home, or memories of one’s homeland, to the places and spaces where one is geographically located.

I also recognize the evocative and provocative potential of using poetry within my doctoral scholarship as a scholar of African descent. I realized that my Ph.D. thesis is its own social performance, where I could articulate dominant norms of intellectual subjectivities to legitimate
myself as an academic scholar. Instead, I use arts-based methods to trouble dominant notions of social science prosaic scholarship; performing artfully through poetic narrative inquiry becomes a transgressive act. My methods also derive from community engagement; my thesis was an opportunity to integrate culturally responsive knowing practices found in my interactions with women of African descent. So, I turn to performance narrative methodologies to challenge the academy to open up space for other ways of knowing, and to broaden our understanding of what is *scholarly* and *valid* in doctoral knowledge generation.

However, as a critical practitioner of performance narrative methodologies, I am also critical of its usage, including its emancipatory potential and of it being *tools of our own*. For instance, performance narrative methodologies as kinesis should not ignore the mimetic nature of narrative, or its potential to reproduce social discourse and its social relations. Elin Diamond (1996) testified to the dangers of reiterating dominant norms though narrative performances; they became “risky and dangerous negotiation between a doing (a reiteration of norms) and a thing done (discursive convention that frames our interpretation)” (Diamond, 1996, p. 5). Alternatively, D. Soyini Madison realized performance inquiry could offer a “performance of possibilities” (Madison, 2003); she recommended using analytical techniques that troubled dominant narratives and offered alternative ones. Deconstructive narrative analysis could unveil naturalizing narratives, subsequently troubling what is perceived as truth, normal, and what should be (Langellier, 1999).

While I revel in the cultural congruency and responsiveness of performance narrative methodologies across continental African and African diasporic cultures, I also grapple with what that means exactly. Many authors attested to the prominence of narrativization practices amongst the cultures of peoples of African descent (DeFrantz & Gonzalez, 2014; Gilroy, 1993;
Ojaide & Sallah, 1999); these claims presume a commonality across continental African and African diasporic cultures. Although, I politically use the term “Africentric” as part of a broader decolonizing project of cultural affirmation, reclamation, and consciousness, I also recognize that in positioning performance narrative as an Africentric knowing practice can potentially essentialize and ahistoricalize its evolution. As much as I long to exist in an imaginary where colonial projects have not sullied the ways in which I know, that I am writing to you using a European language demonstrates otherwise. As peoples of African descent, our ways of knowing, the Narrators and myself, have been shaped by the multiple locales within which we have been historically constituted. Moreover, our constitution of European metropoles stemming from histories of colonization are represented in our knowing practices (Hall, 1990).

Some scholars of African descent attest to the commonality of our cultural practices as returning to “the source” of our African ancestral ways of being in the world; I think, however, that the gravitation to narrative knowing for peoples of African descent is more complex.

Colonization as a process of cultural erasure and racialization has resulted in the ingenuity of peoples of African descent to remake their knowing practices such that they collectively know anew; this knowing anew often became local knowing practices. As such, our local ways of narrative knowing have become reflexive practices that re-member our indigenous ways of being in the present-day, a resourceful practice that serves as anti-colonial resistance and decolonizing reclamation. Narrative as a doing practice in Africentric cultures can preserve local knowing practices, counteract Euro-Western centrism and remake local practices such that they suit contemporary contexts. So narrativization as a cross-cultural practice amongst peoples of African descent can be attributed to the commonality of oral narrative in many continental African and African diasporic cultures and its knowledge preservation potential, as well as to the
ingenuity of African descendant thinkers to remake narrative practices that re-member indigenous practices of communication. That performance narratives in the oral tradition feature in many continental African and African diasporic art forms — spoken work, reggae, Afro-beat, spiritual oratory amongst others — testifies to a shared understanding of its function — cultural kinesis — whether that cultural action is preservation, subversion, counter-action, resistance, or conscientization.

As much as I desire to decolonize my ways of knowing, this process cannot erase the European presence within them. However, instead of conceding to it or resisting it, performance narrative knowledge generation in the decolonizing, anti-colonial and transnational feminist traditions allowed me to grapple with and troubles it. This grappling and troubling engaged my second sightedness (Du Bois, 1903/2006), seeing the world through my Euro-Western and Afro-Jamaican ways of knowing. This second-sightedness made me more translocally conscious of the multiple ways in which I viewed the world as a second generation Canadian located in two worldviews – the Caribbean and the Canadian, and how the women I interviewed may make sense of the world in similarly sighted ways. It also required me to critically reflect upon the tensions of the European presence as Eurowestern centrum within academic knowledge generation. This second sightedness and translocal consciousness demanded that I critically perform this grappling and troubling within my writing. So, despite the tensions of positioning performance narrative methodologies within Africentric cultures as tools of our own, I also feel compelled to do so politically, and personally: to emphasize that emotive and embodied ways in which people of African descent can know the social world, and to etch out space for it in the academy. Many scholars of African descent have emphasized the decolonizing potential of these tools of our own. However, let me preface tools and us. For this study, “our” refers to the women
of African descent who engaged in the methodological development for the Because She Cares study: the community advocates with which I conversed, the Narrators, and myself. “Our tools” include the embodied, emotional, historical and cultural wisdom and modes of resistance and resilience from which we generate and share knowledge.

To conclude, I used performance narrative methodologies for the Because She Cares study because of their kinetic function: to evoke and prove. My approach to narrative research evoked sensory, emotive, embodied, and cerebral ways of knowing. It also provocatively used methods of representation that blurred disciplinary boundaries between the humanities and the social sciences. But I also drew upon performance narrative methodologies to provoke YOU … yes you, the reader of this thesis. What does it DO TO YOU when I speak to you in the first person? When I incorporate a poem instead of a quote? When I premise my feelings in my analytical thinking? When I present narratives of caring work in a dissertation that practices caring work vis-à-vis the study of it? What does it do to you? Not just mentally, but emotionally, bodily, reflectively, and sensuously?

I recognize that the audience of this thesis may be varied and intersecting: social work academics, social scientists, HIV researchers, and racialized scholars, including scholars of African descent. I also expect that workers in HIV sectors, including employers in the Canadian HIV sector may read this thesis as well. Yet, I believe there are passages within this thesis that may evoke and provoke each of, and all of YOUs, albeit in different ways. As such, I want to PROVOKE you(s)….

To feel. The stories of African women living with HIV.

To consider. The narratives that have been diminished or erased.

To reflect. On social narratives of civic engagement.
To think. About engagement in HIV responses a little differently.

To embody. The tensions that derive from conducting this research.

To learn. From these tensions as well.

To understand. HIV caring work with, for and by African women living with HIV.

I want to provoke YOUs.

If I can evoke your senses, your reflections, your doubts, your concerns, your own grappling and troubling with this subject matter, then perhaps this doctoral study can evoke new understandings of HIV-related work as caring work and provoke methodologies that transgress the cultural norms of Canadian academic scholarship.

**Narrative terminology used in the study.** I primarily use the term *narrative* to define both the methods used to gather stories and oral accounts gathered. I use *story* to denote a storyline that resonated in a person oral narrative which in turn became a focal point of narrative analysis and representation. Although *storytelling* is a common practice in many local cultures of peoples of African descent, including my own (Chilisa, 2012), I refrained from using this term as the narrative approaches used did not faithfully follow Africentric storytelling practices. However, I do use *story-telling* to denote the practice of repeating a storyline, and *retelling* to emphasize the practice of relaying a story to others when one is not the originating teller. I use the term *re-membering* (instead of remembering) to highlight the purposeful sensemaking of the past through narrativization.

In lieu of using the research term *participants*, I use the term *Narrators* to emphasize the active engagement of the women who shared their stories and recognize their co-creation of knowledge generated on this study. Using the term Narrator emphasizes that the narrative practices used in this study are based on oral narrative traditions, and narrativization is an active
process of sensemaking. I use Narrators as a proper noun when referring to the women I interviewed explicitly; and narrators as a common noun when I speak of potential study participants.

I found the ways in which I engaged narrative methods became an active process of witnessing and honouring the story-telling process; I was moved by the experience of listening to these stories and was emotionally impacted. Bearing witness, or being an empathetic and receptive audience to African women’s stories, shifted my understandings of HIV-related work as caring work. I use the term bearing witness to emphasize the empathetic and transformative process of active listening where I not only listened to Narrators stories but strived to receive their messages and learn from them as well (Comas-Díaz, 2000).

How I Acquired and Shared Knowledge (Methods)?

Inviting the Narrators (Recruitment). I invited immigrant women of African descent to serve as the Narrators for the Because She Cares study. To be eligible, narrators had to self-identify as HIV-positive and of African descent who immigrated to Canada as an adult (age 20-64) and were currently living in Ontario. Narrators had to live in Canada for a minimum of three years and have had prolonged engagement (two years or more) in Canadian HIV responses that included one or more paid positions (i.e., HIV-related employment). I invited narrators whose time working in HIV responses varied from newly engaged since coming to Canada to long-standing engagement that preceded their migration. I focused recruitment in areas of Ontario that had significant services for African people living with HIV and AASOs that hired peoples of African descent.

People living with HIV may interchangeably work in voluntary or paid position in the HIV sector, and their entry and engagement in HIV response activities in general may shape their
sensemaking of their HIV-related employment. Thereby, I used prolonged engagement — paid or unpaid — rather than employment tenure as inclusion criteria. I wanted the inclusion criteria to recognize that due to the episodic nature of HIV, people’s employment in the HIV sector may vary due to the accessibility of employment, the availability of paid work opportunities, and personal work preferences. Employees in the HIV sector may work temporarily or contractually over a limited timeframe in multiple paid positions while still engaged in the response voluntarily, or they may choose to step away from paid employment but remained engaged as a volunteer. Moreover, their transition into paid work may have begun from voluntary work such that the delineation between paid and voluntary work may not be distinct.

I used purposive sampling to locate narrators. Purposive sampling created a sample based on the relevance to the research question, and my theoretical understanding of HIV-related employment (Mason, 2002). Purposive sampling was an ideal approach for this study as my area of inquiry explored caring work from a particular viewpoint (immigrant women of African descent living with HIV) that has been under theorized in the literature. As well, my sampling strategy assumed that immigrant women with HIV who have migrated from other nation-states may conceptualize caring work that draws on various national contexts. I engaged peer networks and community champions in African, Caribbean and Black (ACB) communities to help me locate narrators. Peer networks included friendship networks for people living with HIV, support groups, and peer worker collaboratives where people living with HIV employed in specific positions (i.e., front-line support workers, peer researchers) connected with other like-minded employees to knowledge share and provide instrumental support. I also had assistance from community advocates who promoted the study amongst their contacts. Ten women of
African descent who identified as African (i.e., homelands in continental Africa) participated on this study.

**Knowledge gathering (Data collection).** To gather work stories, I conducted a series of one-on-one oral narrative interviews (2-4 interviews). I also captured my reflections using reflective journaling.

*Oral narrative interviews.* Oral narrative is a data collection approach where people narrate experiential stories to an audience and draw upon memory, context, emotions, and audience interaction to engage meaning (Berger & Patai, 1991; Labov, 2009). Oral narration of one’s personal experience can become oratory performance: where a narrator performs the parts of one’s life they wish to share or keep silent, or shape what stories are conferred based upon the immediate or perceived audiences. Oral narrative as a data collection method is congruent with many Africentric cultures as oral narrativization have become a cultural practice of preserving and sharing knowledge (Chilisa, 2012). Oral narrative as knowledge gathering is also congruent with decolonizing and transnational feminist frameworks as it valorizes lived experiences, and allows narrators to lead the process (Vaz, 1997).

To gather oral narratives, I used a relatively unstructured interview guide (See Appendix 1). The guide included a preliminary open-ended interview question on HIV-related work (e.g., “Tell me about your experiences of HIV-related work.”) and closing interview questions that aim to gather work aspirations and recommendations for improving work in the Ontario HIV sector. The use of a primarily unstructured interview guide allowed the Narrators to *let the stories flow* (Chambers, 2019, anticipated), a non-directive knowledge gathering practice that gave the Narrators greater control over the direction of the interview, such as discussing experiences that they felt were particularly salient to their understanding of HIV and work. While the interviews
were conducted in English, the Narrators were encouraged to use their local languages if some ideas or concepts were best conveyed that way such as cultural precepts of work. When local languages were used, I would request translation in follow-up interviews.

While the narrative portion of the interview was unstructured, I also asked semi-structured demographic questions at the beginning of the first interview. I gathered demographic details on geographic and tenure-related information on work (paid and voluntary) such as what HIV-related work they have had in Canada, their homeland, or other geographic locales, what non-HIV related employment they have had, and the length of time they worked at these jobs (See Appendix 2 for demographic form). I used this demographic info to prompt on time- or place-related aspects of work that I could probe in future interviews such as HIV-related work experiences in the past or in their homeland that was noted in their demographic information but not featured in their initial work narratives. I also found that the Narrators used their responses to demographic questions to situate their narrativization of HIV-related work. Many of them began their narratives as I asked demographic questions. For instance, questions asking about specific HIV-related work in a particular geographic locale elicited narratives of work including memories of their HIV-related work in their homeland, or time-points in their lives (moment of HIV-diagnosis, migration to Canada) that became critical turning points.

While employment in the HIV sector was a primary focus of this study, I was also mindful that the Narrators’ understanding of “work” and “engagement” in HIV responses may differ from my own. Some of the Narrators reflected on their work outside of the HIV-sector such as emotional support, caregiving, or mothering as part of, or relevant to their HIV-related employment. Others considered their employment outside of the Sector as integral to how they understood their HIV-related work. Thus, the Narrators drove the direction of their
narrativization while I would use prompts get more information or clarification on the temporal, spatial or relational aspects of HIV-related work which featured in my analysis.

During the interview, I was particularly attentive to what may not be recorded on tape such as facial expressions, body language, and emotive expressions. I took notes during the interview to identify non-verbal communication that may not have been recorded on tape (e.g., body language). When appropriate, I would clarify with the participant what their actions meant. For instance, if a participant offered a look after I asked a question, I would state what I saw and ask for its meaning (You seem to give me a quizzical look after I asked about your work back home. May I ask why?) If they expressed a strong emotion — crying or anger — I would attend to their affect (i.e., ask if they wish to pause). If they wished to continue, I would ask them about why they were expressing such emotions. I saw these non-verbal expressions as part of the conversation we were having and would prompt these expressions in the same way I would prompt verbal communication that required further clarification.

All interviews were audio-recorded using a digital recorder and transcribed verbatim. To ensure that non-verbal communication was also included in my interpretation of interviews, I transcribed structural aspects of narrative communication — emphatic expression, body language, vocal quality, speech pacing — into transcripts. The notation style used for my thesis drew from Jeffersonian Transcription Notation used in conversation analysis (Jefferson, 2004) as well as modifications made for poetic transcription as recommended by D. Soyini Madison (1993, 2011) and Catherine Kohler Riessman (2008). (See Appendix 3 for transcription notion key used for study).

Multiple narrative interview sessions were originally desired as narrative interviews can often be lengthy exchanges. Also, as per the common practice of oral narrative interviewing, I had
originally planned to keep interviews to around two hours and to book additional interview as required. Yet, these data collection methods were ill-suited to the interviews I was conducting; it assumed that I, as interviewer, controlled the exchange. Instead, I drew upon my own cultural understanding of narrativization as a story-telling event that is both shaped by the narrator — the stories they felt compelled to share at the time of the telling — and the audience — my engagement with the story as influential in what is told. Additionally, many of the women I interviewed felt compelled to talk about their HIV-related work. For some, it provided an opportunity to reflect upon their work in HIV responses in multiple locales. For others, they consider this study as an opportune time to critique HIV-related work in a particular locale. As a researcher who worked in the Canadian HIV sector, and a potential employer of people living with HIV, I felt compelled to listen. So, we — the Narrators and myself — allowed the interviews to take their course, with interviews ranging from one to four hours, and the average interview being approximately 2.5 hours.

My original methods also assumed that narration would be contained within the perimeters of the formal interview. However, whenever I checked-in with the Narrators, a couple of days after their first interview, the conversation would often continue off-tape. In some cases, the Narrators continued the conversation via text and email exchanges, which would filter into my reflective journaling and when applicable future interviews.

For the most part, the Narrators preferred to complete one oral narrative interview; however, when I conducted follow-up interviews to review preliminary analysis, the Narrators often added to their work stories. These follow-up interviews were also recorded and comprised data collection. I speak more about follow-up interviews in the section entitled Workshopping Stories.
Reflective journaling. To aid my analysis, I incorporated reflective notes into my data collection. Reflexive journaling is an interpretive approach to field notes that allowed active reflection of the knowledge gleaned from the interview encounter: what I learned from the Narrators’ stories and from other knowledge sources that I encountered, what I experienced from the narrative, and what I learned from the narrative inquiry itself. While field notes are a common practice in qualitative inquiry, reflective journaling goes further by noting the why’s and how’s of inquiry. Why do we — as inquirer or Narrator — engage in narrative inquiry in the manner that we do? How do the Narrators’ stories shift my understanding of the research topic? In my reflective journaling, I strived to be “consciously aware” of what is going on in the research process, and to connect this with social positioning, social interaction, prior knowledge, and new knowledge gleaned from the inquiry (Clandinin & Connelly, 2000).

Immediately after each interview, I audio recorded my impressions of the interview. These reflections included a description of the narrative environment (i.e., where the interview was conducted, the length of the interview), a summary of the work stories shared by the Narrator and my initial reflections of HIV-related work as caring work based on what the Narrator shared. This initial interpretation often reflected on what I knew so far (background readings, other interview narratives, previous reflections from other interviews) and how the interview challenged or extended what I knew. In my reflective journalling, I would incorporate these audio-recorded reflections. I also paid particular attention to the scene (i.e., interview location, prior relationships, interactions before, during, and after the interview) and the performances of the Narrator and myself (our performance roles, social positioning, and relational positioning throughout the interviews). These reflections also documented emotive aspects of the narrative experience that are typically not audio-recorded such as the Narrator’s affective states during the
interview, and my own affective states preceding, during and following the interview: What emotions were expressed during the interview? Were these emotive expressions shared? Did we both laugh? Was I surprised by her expression of anger? Was I prepared for her tears? How did her stories affect me? Did I express to her how I felt? Was I still emotionally affected by the interview after it ended?

What I recorded in my reflective journaling was not just my impressions of the interview, but my experiencing of the narrative encounter. And these experiences filtered through my positioning as a doctoral student, community-engaged researcher, social worker, HIV-related worker, racialized woman, second-generation Canadian, person of African descent, advocate, and care worker. These dialogic positionings — positioning myself and the Narrators’ in the interpersonal context of the interview and in the broader context of social relations — became interpretive frames from which I understood their experiences of HIV-related work as caring work. As such, I found these journaled reflections influenced my interpretation.

This self-reflexivity — positioning oneself within the narrative performance — is a common approach to performance narrative inquiry, where authors such as Kristin Langellier (1999) and Catherine Kohler Riessman (2005) reflected upon the ways in which self-identities and social performatives are articulated within the narrative inquiry, shaping interpersonal relations between the interviewer and the narrator, as well as our interpretations of the narrated and narrative experience. Often narrative inquirers will take up this self-reflexivity into their writing style, where they position themselves more within their work than what is typical of academic research. D. Jean Clandinin & F. Michael Connelly (2000) emphasized the importance of reflexivity in narrative research as it fostered greater awareness of the inquirer role in shaping the narrative dialogue. Notably, self-reflective writing is commonly practised in decolonizing, anti-
colonial and transnational feminist thoughts, where there is less delineation between experiential knowing and knowing through other sources (Anzaldúa, 1981; hooks, 1990). Instead, we bring our experiential and emotive knowing into our critical reflexivity and theorization.

**Narrative interpretation (Analysis).** To attend to the emotive and political potential of these narratives, I incorporated structural and thematic approaches to performance narrative interpretation (Riessman, 2008). Structural interpretation attended to the ways the Narrators convey their stories and used the interpretation of emphatic expression to identify work stories that resonated. Thematic interpretation identified emerging themes that resonated across work stories in relation to HIV-related work as caring work: ways in which African women living with HIV understood their HIV-related work as (trans)local practices of self, communal or social caring. Interpretation was also embodied and dialogically experienced: I was attentive to how certain segments of interviews evoked and provoked me emotively and intellectually during the narrative experience and interpretative process. I found my continuing dialogues with the Narrators during the data collection and interpretation stages influential to my interpretation; when sharing my preliminary interpretations with the Narrators, I paid attention to aspects of their stories that resonated with them and incorporate this in my interpretations.

Narrative interpretation was a multi-stage process that involved interpreting the narrative experience, deeply listening to oral narrative interviews, reading interview transcripts, summarizing individual work stories, finding poems within oral narratives, and conducting structural and thematic analysis. I also met with the Narrators individually to workshop the poetic retellings that I had interpreted as relevant to their sensemaking of caring work. My interpretive approach primarily drew from Catherine Kohler Riessman's (2008) performance/dialogic narrative analysis. I used the sociolinguistic methods of James Gee (1985),
Laurel Richardson (1992, 1993, 2002), and D. Soyini Madison (1993, 2003, 2008) to represent the poetic aspects of narratives. Guided by the work of transnational feminism scholars who incorporate arts-based approaches within their work, I *poetically and narratively retold* emotionally, politically and theoretically resonating stories of caring work in the context of HIV found in the narratives of the African women who originally told them.

**Interpreting narrative experiences.** During the data collection process, I became very attentive to how the Narrators were sharing their story, and how I bore witness to their stories as an interviewer, inquirer, and audience member. As interviewer-inquirer-audience, I become acutely aware of what these stories could do if retold in a manner that brought forth what I was experiencing in my interpretation of them. As an inquirer, I felt compelled to be as attentive to the story-telling aspects (narrated experience) as I was to the story told (narrative experience) and noted these narrative experiences within my reflective notes; I then incorporated these reflections in my interpretation and my poetic representation. Interpreting narrative experience attuned me to the deep listening required for poetic and performance interpretation of oral narratives.

*“Deep listening” to oral narrative interviews.* As my interpretation was grounded in the oral narrative tradition, my initial interpretation of the Narrators’ work stories involved a *deep listening:* listening to each interview multiple times to interpret the narrative experiences of HIV caring work, and decipher my and the Narrators’ reactions to the stories told. The purpose of multiple listening was three-fold: first to transcribe and edit the interviews; then to transcribe narrative performance (i.e., paralanguage, tone, emphatic expression, etc.); then finally to re-engage in the dialogic process of the narrative experience. Deep listening at various stages of analysis allowed me to get a sense of the performance aspects of the narrative including verbal
(i.e., the language used) and non-verbal communication (body language, vocal tone, pauses, silence, repetition etc.). This process also allowed me to become accustomed to the Narrators linguistic styles. As I listened, I would become accustomed to their narrative rhythms, local languages, repetitive words or phrases, speech pacing, and emphatic expression captured in the recording. I also listened to the narrative to re-engage with the Narrators and their work stories. In these later moments of listening, I strived to hear what work stories featured within each narrative, and how they were relayed. Did they try to emphasize certain parts of their work stories using emphatic expressions or repetition? How were time and place narrativized? Were there certain work stories that particularly resonated with them, as illustrated by the emotions they conveyed when telling them? Were there points in the conversation where I became a character in their story, where they directed the conversation to me, said my name, challenged a question, or responded through silence? Did they perform their story through analogy, song, emphatic expression, or mimicry of other characters? I would allow this listening to take me back to the interview and try to be attentive to what stories seemed seminal to the Narrators’ sensemaking of caring work.

Deep listening also awoke sensory, emotive, and embodied practices of interpretation. As I listened, I would be attentive to what the narrative was doing to me, which parts evoked bodily tensions or emotive responses. I was also attentive to how the interviews made me feel. I would note places in the interview where I got emotional while re-listening — stories that made me laugh, made me frustrated, made me cry, made me pump my fist and go “You go, girl”. As audience, I strived to be attentive to what listening to these oral narratives were doing to me, making me feel, teaching me. This deep listening went beyond listening for the words that were said but to how the words resonated: as performance text, oratory expression, emotive
interconnections, and political implications. Thus, I experienced the narrative experience — the interview — in the process of deep listening.

I found the deep listening experience pertinent to performance narrative interpretation. Performance narrative strives to tell stories to significant others: persons who will experience a connection to the story relayed (Plummer, 2001). Consequently, this interpretation process did not solely engage my cerebral ways of sensemaking, but my emotive ways as well. This emotive knowing allowed me to engage deeply with the narratives and recognize what work stories were particularly salient to Narrators’ sensemaking of their HIV-related work as caring work. It also trained my poetic instrument, as emotive ways of knowing are pivotal to poetic interpretation and representation (Leggo, 2008). More importantly, I wanted to recognize interpretation as a co-knowing process, where I interpreted through “bearing witness” to the Narrators’ narrativization of their stories. In bearing witness, I became acutely aware of what these stories could do — emotively, bodily, reflexively, dialogically — if retold in a manner that brought forth what I was experiencing.

Reading interview transcripts. I also read the narrative transcripts to develop my understanding of the caring work stories that underlie each narrative. The literature on HIV engagement, caring labour, and transnational work guided my reading, but I was also attentive to work stories that were not commonly discussed in the literature. In my initial readings of the interview, I identified the self-, collective, or social caring work stories that emerged in each narrative such as type of work (e.g., AASO work), caring work roles or responsibilities (e.g., activist work, kin work, mother work), or the work in the context of health and well-being (e.g., health work, stigma work). As the transnational literature has noted the importance of temporal and spatial dimensions in making meaning of one’s experience of work, I also noted time or
place as it featured in stories: work experiences within or outside of the HIV sector; past memories, present experiences, or future aspirations of work; and the locales within which work was experienced, contextualized, or narrativized.

**Summarizing individual work stories.** After reviewing the narrative transcripts, I would write a summary of the work experiences comprised in each Narrator’s narrative, grouping these experiences based on the context of their caring work (self, interpersonal relations, workplace, community) or work roles identified (“sister”, “activist”, “mother”). These groupings became *HIV caring work stories*: experiences of work that were seminal to each Narrator’s sensemaking of their HIV-related work as caring work. Along with the summary, I would note particular work stories that featured prominently in their interview(s): stories that comprised a significant part of the narrative, evoked strong emotions, or deemed relevant by the Narrator. Using mindmapping techniques, I would then map out the HIV-related work experiences of each Narrator.

Mindmapping provided me with a visual map of their “working life”, including where and when this work featured in their life, which aided thematic interpretation. In follow-up interviews, I also used mindmaps to confirm what work stories were featured in interviews.

**Finding poems.** Finding poems was a process of interpreting and representing narrative data poetically such that non-verbal communication and emphatic expression were incorporated in their representation. The aim of finding poems within narrative data was to “represent significant moments in lived experience” (Richardson, 2002, p. 880) or to emphasize what I interpreted as key experiences of caring work. I also use poetic representation to capture the performance of the narrative experience; poetry served to speak for what is often silenced in narrative text — metaphor, lyrics, emotions, imagery, rhythm, pacing — such that the storied performance is brought back to the text (Hordyk et al., 2013). Finding poems is a dialectic
experience that ignites other ways in which we interpret our social world: sensually, emotively, cerebrally, and embodied.

My process of finding poems was descriptive and interpretive. The descriptive process came from transcribing non-verbal communication and empathic expression within the text (i.e., poetic transcription). The process derived from interpreting the Narrators’ interviews for emotive, political or theoretical resonance: emotive resonance where powerful emotions were aroused in the Narrators or me during narrative sharing, witnessing or interpreting; political resonance where the Narrators declared calls for action that related to their work in HIV; and theoretical resonance, or passages that conceptualized HIV-related work as HIV caring work. This search for emotive, political or theoretical resonance typically derived from the narrative experience: how the Narrators told their work stories, and how their story-telling evoked emotions or provoked further reflection. What I also found was that these evocative and provocative passages held theoretical resonance, as the poems illustrated the Narrators’ experiences of HIV caring work as people engaged in local and transnational HIV responses.

While listening to oral narrative interviews, I would review the transcribed interview and highlight passages that resonated with the participant or myself. Then I would add an in-vivo code — a phrase from the narrative that names the passage — to collect like thoughts together. Sometimes these passages were only a paragraph or two, other times these passages ran several pages or occurred at multiple points across a transcript (See Appendix 4 for example of poetic transcription). I later transferred my coding from the transcript to Max QDA so that I could group like passages using the same in-vivo code.

Next, I would extract the coded passages and output them into MS word. Using James Gee’s (1985) sociolinguistic process, I would break the passages into lines, stanzas and parts as per the
poetics of the oral narrative (natural breaks illustrated through commas, periods, or changes in the topic). I would often re-listen to the interview to ensure that the rhythm fit with the original oral narrative performance. Then, I would edit the text such that the poetic resonance that I experienced as audience and interpreter was also expressed within the passage. While I strived to keep close to the Narrators’ own words, sometimes I would remove words, or move passages for emphasis, or anonymize passages such that the Narrator’s confidentiality was maintained. I also grouped like passages together if they illustrated similar ideas though they may occur at different narrative time points. Resonant passages were “retold” as poems (i.e., poetic retellings) using poetic devices (i.e., metaphor, repetition, visual-textual representation) to embody the emotive resonance of the original narrative telling and evoke the theoretical and political relevance of the sharing (See Appendix 5 for examples of narrative passages interpreted as poetic retellings). This process was non-linear, reflexive and dialogic: poems were reshaped because of reflections that arose from the interpretive process and after conversations I had with the Narrators when workshopping their stories.

**Workshopping stories.** I used workshopping processes to verify interpretation, and to gauge the resonance of poetic retellings and the Narrators receptivity of them. In the performance arts, plays in draft form are performed to gauge audience reaction and their critique (Le Cordeur, 2008). Workshopping recognized the dialogic aspects of validating interpretations with the Narrators while acknowledging that my interpretations may differ from theirs. Once I had summarized the Narrators’ stories, crafted a mindmap of their working life and drafted poetic retellings, I would meet with them individually to summarize the work stories that featured within their narratives, and identify stories that featured in my interpretation of their work as HIV caring work. I also shared the poetic retellings deriving from their narratives —
orally and in writing — and provided the passages from original transcript along with the retellings so that they could see their narrative origins. I also noted places in poetic retellings that I may have edited to confirm that the changes did not alter the meaning of the originating story. While I offered the Narrators the opportunity to actively engage in poetry writing themselves, such as editing or adding to the existing poem, most of the Narrators preferred to witness the poetic retelling as an audience member and offer their reflections. In this witnessing of their poems as an oral retelling, they guided the editing process: noting what parts I should edit or add to, and what other passages they wished could be poetically expressed.

During the workshopping process, I let the Narrators know the limits of what I could poetically transcribe. If narrative passages contained too much personal info that to edit it would change its meaning entirely, I would not attempt a poetic interpretation. In other cases, I found that piece of texts, while descriptive of an experience, lacked emotional resonance. This often happened when a narrator was describing a process (this is what I do in my job) without reflecting upon how they experienced it (how they felt about the work they were describing).

This workshopping process helped interpretation as our dialogues aided my identification of stories that were integral to the Narrators sensemaking of their HIV-related work as practices of caring. Workshopping poems also became their own narrative experiences, a reflective and dialogic process, wherein switching our roles — the Narrators as an audience, I as orator — we both engaged in the interpretive process of resonance. The Narrators commented on what resonated for them in hearing their work stories poetic retold including what emotions were evoked or provoked in the telling, or what passages could have political resonance if shared. Some Narrators reflected upon their work differently after hearing the poetic retellings; others found the retellings evoked insights they wanted incorporated.
The workshopping process also began knowledge translation and mobilization (KTM) planning for Because She Cares. Many of the Narrators strategized ways to share the stories outside of this thesis such as hosting community dialogues, publishing them for distribution, or presenting them at conferences, where community members and employers would be present. We also discussed the evocative and provocative potential of sharing research findings in a creative way such as spoken word performances, or a poetry anthology. Workshopping shifted the knowledge generation process, as the Narrators became more actively involved in interpretation as well as planning knowledge sharing/mobilization post-thesis. Most importantly, workshopping and sharing the poetic retellings with the Narrators, allowed me to reciprocate the knowledge that they shared with me.

**Performance narrative interpretation.** I was guided by Catherine Riessman’s (2008) approach to performance narrative analysis to interpret key themes emerging across narratives. Riessman’s performance approach emphasized the structural and thematic elements to oral narrative sensemaking; interpretation uncovered stories that were narrativized as well as the cultural narrative constituted (Riessman, 2008). D. Soyini Madison’s (1993, 2008, 2011) approach to narrative interpretation and representation aided my own as she harnessed the catalytic aspects of narrative performance such as stories that have political resonance.

I used thematic analysis to find conceptualizations of HIV-related work as a caring practice (HIV caring work). I reviewed the narrative data that I compiled for each participant (i.e., coded narrative transcripts, reflective journaling, work story summaries, mind maps, poetic retellings). Then I conducted thematic analysis to identify emerging themes of HIV caring work within and across narratives guided by the following questions:
How is HIV-related work self-, collective, and social caring?

How does time and place (translocality) feature within narrativization of HIV-related work as caring work?

How is caring work shaped by social relations (HIV, gender, ability, ethnic, racial, national and others) within locales and across transnational social fields (translocal intersectionality)?

Using the background and theoretical literature on caring labour, transnationalism, translocality, and HIV work engagement as a guide, I looked for cultural narratives of work (e.g., HIV culture, African culture, Canadian culture, neoliberal capitalist cultures) that articulated what is socially or culturally expected, or what I define as “should be” work; and social relations (e.g., gender, race, ethnicity, nativity, immigration status, ability, HIV-status) that emerged within one’s work performance, or what Butler defines as social performatives (Butler, 1999).

Theories of translocality aided analysis of time and place as they emerged within narrativizations of work (i.e., re-membering one’s homeland, comparisons of one’s homeland with Canada, reflecting on the past or future in relation to their HIV-related work). Interpretation was also attentive to gendered geographies of power that could shape sensemaking of one’s work as a caring practice (S. E. Alvarez, 2014; Mahler & Pessar, 2003). I used translocal intersectionality to understand multi-sited systems of social privilege and oppression that African women living with HIV navigated as workers in continental African homeland and Canadian contexts such as how their social positioning as workers in HIV responses shifted across local contexts. Incorporating transnational feminist theories in my narrative analysis allowed me to consider the multiple or supranational patriarchal contexts within which gender performatives are constructed.

Transnational feminism recognizes patriarchies as multi-scalar: it locates analysis within the
multiple locales of women’s experiences yet considers the global forces that are also in play. In relation to the Because She Cares study, this multi-scalar perspective allowed me to better understand the varied gender relations within which African women living with HIV make sense of their HIV caring work yet situate it in the broader context of neoliberal capitalism, colonialism, migration, and transnational care work.

I used narrative deconstruction to unsettle social performatives as they emerge within personal narratives. It is in this interpretive unsettling that we create space to question essentialized cultural narratives of work and articulated social relations as they emerge within personal stories which Kristin Langellier (1999) speculated allowed cultural narrative and their relations to become “discussable”. My narrative interpretation was also attentive to *agential performances* or narrative passages where the Narrators troubled cultural narratives of caring work or strived to resist how they should care through their work.

I used structural analysis to illuminate overarching themes. Using work summaries, story maps, and reflective and interpretive notes, I would identify particular work stories of individual Narrators that best responded to a theme resonating across multiple narratives. When I found work stories that amply captured an understanding of HIV-related work as HIV caring work, I would focus on the performance and performative aspect of the featured story: language used to convey their work as a caring practice, emphatic and narrative expression that emotively or provocative resonated, featured body language or dialogue that brought me to these particular work stories, and the poetic retellings that resonated within these stories of work. Structural analysis assured that I selected work stories and corresponding retellings that resonated in the Narrators’ sensemaking of HIV-related work as caring practices with, for, and by them as African women living with HIV.
Performance narrative representation. Narrative representation plays an important role in performance narrative research as a decolonizing methodological practice as it becomes the opportunity for the Narrators to be featured as knowledge generators and represent findings that illuminate the Narrators’ sensemaking (theorization) of their experiences. When done artfully, it strives for an evocative portrayal of the narrated and narrative experience, displaying emotions, nuanced ideas, and underlying meanings that prosaic representations may not capture (Glesne, 1997).

My approach to performance narrative representation was to position the Narrators’ sensemaking of their HIV-related work as the genesis of my interpretations of HIV caring work. Poetic retellings featured strongly in this thesis as they illustrated what aspects of HIV caring work resonated in the Narrators’ work stories. Often in lieu of quotes, I featured stanzas or an entire poetic retelling alongside findings. I chose to use poetry to anchor each Narrator’s story and illustrate what aspects of HIV caring work emotively, theoretically and politically resonated. I also used poetry to evoke the multiple ways — thoughtful, emotive, embodied, emphatic, reflexive — in which the reader may make sense of this thesis. My use of poetry strived to be provocative; I desired to create space for culturally responsive, arts-based approaches within the academy so that others can more easily employ them in their doctoral research. Lastly, I used poetry as it best represented how I found the Narrators stories of HIV caring work.

In cases where a poetic retelling could not credibly illustrate my interpretation, I would incorporate quotes or dialogic exchanges between the Narrator and myself. I also wrote my interpretations as a narrative commentary of what each Narrator taught me about HIV caring work: I conveyed to the reader my experiencing of the narrative experience, and why certain stories resonated strongly in my interpretations. I was subjectively present in this commentary,
noting my relational positioning within the contexts of the narrative and its relevance to the story told. The purpose of subjective representation was to represent myself as a learner as well as a knower: my understanding of HIV caring work derived from the teachings of African women living with HIV. I aimed to present my interpretations as another narrative account alongside the Narrators’ stories. And similar to the Narrators’ accounts, my own is perspectival, contextual and contingent to the narrative experience: a doctoral research study conducted by a scholar of African descent who is also a worker in Canadian HIV responses.
Chapter 5: Grappling with Conducting Culturally Responsive Knowledge Generation with, for, and by Peoples of African Descent

I found that in striving to conduct this research as a decolonizing knowing practice, I constantly grappled with how to do so. For instance, what notions of research “authenticity” and “trustworthiness” apply when these terms may have divergent meaning in academic knowing practices (derivative of Euro-Western worldviews) and local knowing practices derivative of cultural worldviews of peoples of African descent? What are the moral implications of conducting doctoral research as culturally responsive knowing practices with, for, and by peoples of African descent as the Ph.D. scholar who is also of African descent, and engaged and embedded in the community spaces for which the research is understanding (and critiquing)? What are the moral implications of conducting doctoral research as a decolonizing knowing practice that may differ from the conventional ethical practices of academic research? And what are the tensions of conducting research with and for the people for whom the research is intended in the context of doctoral scholarship? As I recognized that this grappling may differ from conventional sections on “trustworthiness” or ethical implications common in a qualitative doctoral thesis, I decided to make it a separate chapter. Furthermore, I wanted to frame my understanding of ethics using a relational stance, where as a scholar of African descent, I consider the relational implications of conducting research with and for peoples of African descent.

Is It “Valid”? Living with the Tensions of Research Validation (“Trustworthiness” in Qualitative Research)

Of all the sections of this chapter, perhaps this section caused me the most “tension”. And I was not alone. Many qualitative researchers grappled with defining validity in the context of qualitative research, with some such as Yvonna Lincoln, Susan Lynham and Egon Guba
imploring researchers to consider the epistemological frames in which they understood validity in qualitative research: were they consistent with the epistemological paradigms which their research adopts (Lincoln, Lynham, & Guba, 2011)? Additionally, these questions of validity typically gravitated to quality: if validity had been considered, was this a study of good quality? This notion of research validation indicated the external audience who is doing the validation, namely academic audiences. For instance, Lincoln and Guba (1985), seminal work in naturalistic inquiry has been commonly cited as a credible standard for quality in qualitative research. Their criteria for trustworthiness in research included credibility (are the findings believable), transferability (can findings be transferred to other contexts), dependability (are findings consistent with the data gathered) and confirmability (were methods documented in a manner to allow confirmation by others). Maureen Jean Angen (2000) argued however that such criteria engaged in subtle realism, authenticating qualitative research based on post-positivist claims of validity and rigour. It also presumed that authentication of research validity required academic “expertise”.

For those whose perspective of knowledge generation is guided by decolonizing knowing, anticolonial thoughts or, transnational feminist thoughts, the audience for whom the research is with and for should take priority. Bagele Chilisa (2012) suggested that decolonizing knowledge generation should follow a relational axiology: strive to be accountable to the communities to which the research is intended, recognize participants as knowledge contributors, best assure that research is of benefit to communities with which the research is intended, and do more than just speak about decolonization but actually strive to apply its principles and reflect upon its application. Moreover, for colonized peoples, research validation, ethical considerations, and moral implications are interconnected. For research to be of use and of value for the
communities with which the research is intended, it must not only engage in the ethical conduct but also consider the moral implications of conducting this research. Are the stories presented authentic to lived experience? Is the research presented in a manner that is helpful for communities rather than harmful? How is the inquirer represented in the findings? Whose ways of knowing take precedence in the research? Has the inquirer reflected on the context within which the research was conducted including positionalities, power relations and inquirer/participant relations? Will this research do something other than be a placeholder on a bookshelf?

Because of these validatory, ethical, and moral considerations and tensions, I looked for other thinkers who experienced similar tensions around validity and ethical claims in qualitative research with, and for colonized peoples. Guided by Maureen Jane Angen (2000) evaluative criteria for qualitative research and Bagele Chilisa (2012) and Shawn Wilson (2008) understanding of relational axiology, I offer the following substantive and relational considerations for performance narrative research with, by and for peoples of African descent.

**Substantive considerations.** According to Angen (2000), substantive valuation recognizes the substantial contribution of the work to the audiences for whom the research is of interest. While this includes the academic audiences for whom the research may have some relevance, it also acknowledges that the research should chiefly contribute to the communities for whom the research references. Substantive valuation also recognizes the co-created process of knowledge generation, and that human knowledge derives from varied sources — background knowledge, experiential understanding, theoretical and topic literature, conversations with other knowers, participant narratives for instance — and these varied sources should be recognized in our representation of findings. Lastly, substantive valuation requires an account of the process such
as how the inquirer came to their interpretations; this does not negate the contextual, perspectival, partial (and contestable) nature of knowledge, but offers the audience an opportunity to engage with the knowledge so that they can contribute to the dialogue.

To address substantive considerations, I employed a critical, praxis approach to knowledge generation. I devised an epistemological framework that troubled colonial artifices within academic research and positioned knowledge generation as social justice praxis. In incorporating anti-colonial, decolonizing and transnational feminist thoughts within my theoretical framework, I became better aware of Euro-Western supremacy and erasure of subaltern viewpoints and incorporated methodologies that brought forth the wisdom of transnational feminist knowers, notably women of African descent, whose lived experience foregrounded my knowledge generation. I also strived to address the supremacy of academic knowledge sources in knowledge generation through an equitable recognition of various sources of knowledge (e.g., lived experience, dialogues, background literature, theoretical literature, topical information) in my presentation of findings, positioning the Narrators knowing as the primary source of my interpretations, with other knowledge sources guiding them. I also allowed multiple ways of knowing (i.e., experiential, emotive, cerebral, embodied) to guide my sensemaking. This multi-knowality — multiple sources of knowledge, and modes of knowing — was congruent with a decolonizing perspective, where all sources of knowledge should be equitably recognized and honoured in our methodological choices (Meyer, 2008).

My praxis approach to knowledge generation strived to decolonize knowledge gathering within my research practice. I incorporate African philosophical principles of sagacity, where I drew knowledge from women of African descent in devising culturally responsive methodologies. My conversations with women of African descent who were involved in
Canadian HIV responses, guided my selection of performance narrative methodologies as they were culturally responsive to narrative practices common in many Africentric cultures. I also looked to the background literature on oral narrative with and for women of African descent to support methodological decisions. To best assure that my methodological decisions were still suitable to the Narrators sensemaking of experience, I also drew knowledge from them, being attentive to the communicative practices they used to transmit their stories, and their experiential, emotive, cerebral, embodied ways of narrative knowing. As I gathered stories using oral narrative methods, I proceeded to make methodological choices that recognized the sensemaking processes of oral narrativization such as the open-ended dialogic approach to knowledge gathering, poetic transcription and representation of non-verbal communication, and structural and thematic interpretation techniques that recognized narrative as a story told and a story-telling event. This praxis-orientation to knowledge gathering recognized the political nature of methodological decision making; I incorporated culturally responsive methodologies common in Africentric cultures to position them alongside other knowing practices, demonstrating both their utility for Africentric cultures and their soundness within academic research. In drawing upon the knowledge of the sages, I recognized their methodological wisdom, positioned their understandings of sound methodology and methods alongside academic theorists.

A praxis-oriented approach also assures that research is useful and relevant to intended communities. To assure the community relevance of the research topic prior to conducting it, I conversed with women of African descent who are engaged in HIV responses to gauge interest in the topic and talked with ACB AASOs who had an interest in the topic. Though this is a Ph.D. research study, I treated it as an extension of my community-engaged work with, by and for ACB communities. I chose a topic acknowledged as a burgeoning issue in communities of
African descent impacted by HIV and used my research as an opportunity to develop culturally responsive methods in HIV research. Thus, knowledge sharing was a continuous process, including talking with interested parties about the potential application of study findings, and of the methodological implications.

I also went back to the Narrators to assure the study’s relevance to them. In sharing my initial interpretations of their work stories and the poetic retellings that derived from them, I engaged in a verification process that gauge respondent resonance, bringing my thematic and poetic interpretation back to the Narrators to assess how my interpretations of their experience emotively, politically and thematically resonated with them. Kathleen Tangenberg (2000) problematized member checking or respondent validation as it presumes a fixed reality of one’s sensemaking that can shift with context and perspective. Respondent resonance, however, considers how interpretation resonates with the Narrators’ sensemaking of their working lives. Did the findings make sense to them? Do they see the poetry as illustrative of their work stories? Did they connect with the narrative experience of the poetic retelling? Respondent resonance does not presume that the Narrators will agree with my interpretation as we bring different lenses to the topic which may shape our sensemaking; however, it recognizes them as knowledge collaborators who may want to be part of the interpretive dialogue.

A critical approach to research ethics thinks beyond the ethical requirements of research ethics boards when considering benefits and harms. Principally, we should consider benefits and harms within the contexts that participants live, such what confidentiality and anonymity might mean in the context of their day-to-day lives, the potential short and long-term ramifications of consent, and the benefits of adjusting methods to mitigate harms even it reshapes the research questions that get answered. For instance, I thought about issues of consent and their
particularities for immigrant women of African descent, the intended participants of this study. I was mindful of the potential personal harms of participation such as concerns around inadvertent disclosure through study participation. Though the number of women of African descent living with HIV who are employed within the HIV sector is burgeoning, many are selectively open about their status. In focusing recruitment on people who had employment histories in the HIV sector, I also narrowed the pool of eligible participants. As such, they may not feel comfortable participating in a study specifically recruiting employees living with HIV. This recruitment criterion could have contributed to the underrepresentation of women outside of continental Africa in the study; some may have feared the narrow criteria could have inadvertently disclosed them particularly if they believe people from their homeland region are limitedly participating as employees. Moreover, there can be some hesitation to critique one’s employment in the HIV sector for fear such criticism may do collective harm such as discouraging people living with HIV from working in the HIV sector given their critiques of it.

Because of these particularities of HIV-related employment for immigrant women of African descent living with HIV, I addressed these potential concerns within the consent process. As I invited the Narrators to participate on the study, I reviewed the consent form, and discussed potential harms of taking part in the research, approaches we could take to maintain anonymity, and protect confidential such as removing identifying information from narratives passages that are shared. I also spoke about the risk of disclosure in narrative research as interviews are analyzed and represented individually rather thematically consolidated with other narratives. Poetic retellings also required additional consent as they would primarily be used in lieu of quotes and potentially disseminated as poetry books and spoken word performances. I engaged in a separate consent process where I requested permission for each poetic retellings. I
treated this consent process separately to give the Narrators the opportunity to review poems, consider the ramifications of their sharing, request any changes to assure their confidentiality. Narrators could also selectively choose which poems could be shared with others. Given the topical and methodological nature of the study, I was transparent about the potential personal harms of participating in the study, and the limits of confidentiality when conducting a narrative research study focused on a specific group of people working in the HIV sector.

But I went beyond the consent requirements of the REB. Consent was (and continues to be) ongoing: I revisited consent at each meeting and discuss consent in relation to methodological stage (i.e., knowledge gathering, interpretation, representation) and nature of consent (i.e., permission to combine reflections in a collective poetic retelling, or to include a particular poem as a spoken word performance). I also gave the Narrators a date for withdrawal of their narrative data so that they understood the limitations of consent. I continue to speak with the Narrators about the sharing of their narratives such as what poetic retellings of theirs will be featured at academic and community forums. The Narrators also had the opportunity to choose the poetic retellings they wanted featured in a poetry anthology. These conversations have occasionally required the revisiting of consent, but also have allowed the Narrators greater say in knowledge sharing and mobilization. Revisiting consent has required critical reflection around research ethics, and what aspects of ethical knowledge generation is not amply captured through academic ethical protocols.

Ethical concerns also shaped how I represented Narrators stories within the dissertation. As I adapted narratives into poems and wrote my thesis as a long-form narrative, I became more mindful of inadvertent disclosure through narrative representation such as the words people use, the ways they communicate, or the amount of personal detail conveyed in narrative findings. I
strived to choose stories that had some commonalities with other working experiences of African women living with HIV so as not to inadvertently disclose. Through the workshopping process, I worked with the Narrators to anonymize their narratives and poetic retelling which included fictionalizing parts (e.g., the tenure of employment, time-point of migration), and omitting demographic details. I also used workshopping to confirm with the Narrators what details I could share within my thesis, and which work stories I could include in my findings. As I had ten narratives to work with, I decided to focus on five that were representative of other women’s experiences. For instance, participation in liberation struggles features in many African women’s experiences of activist work, so I chose to represent such stories because they had collective relevance. However, I omitted demographics features that could be unique such as counties of origin, and the local languages used to name the struggle. In some cases, I had to omit homeland histories that were particularly unique, or if the Narrator desired such details be excluded. In those instances, I located analysis primarily on work in Canada and ways back home became translocated in Canadian spaces. These ethical choices may have limited the discussion of transnationalism such as contrasting homeland work experiences with those in Canada; yet it also challenged me to interpret how homeland becomes place-made post-migration such as how homeland memories, values, and practices were placed within the Narrators sensemaking of their work in Canada.

Lastly, a critical approach demands reflexivity. I gave detailed accounts of my process, including my reflexive process and how it shaped methodological processes. To acknowledge the iterative process of knowledge generation, I adjusted methods as my understanding of the topic shifted. I also appraise the reader of these iterative processes and the thinking that shaped these choices such as my discussion of “finding poems” in oral narrativization and how I
adjusted my methods accordingly. My account was also self-reflective, using first-person narration within my thesis that take readers through my sensemaking processes and shifts in my thinking. This reflexive account also recognized that the documentation of process should also include the emotive and embodied tensions that arose when conducting research as they serve as a knowing space for researchers, whether they acknowledge it or not. I took this transparent approach because I believe a decolonizing stance demands that we chip away at notions of objective academic expertise by revealing otherwise: research is a subjective, messy, dynamic process; we do not always end up where we thought we would. In taking this intimate stance within academic writing, I desire to trouble research as the privileged form of knowledge generation and reveal it for what it is, another way (not the only way) of making sense of the world in which we live.

**Relational considerations.** Relational considerations recognize our relational responsibility to conduct research that respects the people with, by and for whom the research is intended. This relational regard requires recognition of community wisdom, honours relationship, and aims for research findings that have community utility. Aspects of relational validation addressed in my study include voice, co-knowing, positionality, beneficence, humility, self-care and impact.

*Voice* and its representation feature heavily in decolonizing knowing, anticolonial thoughts, and transnational feminist thoughts. This understanding of voice includes using knowledge generation and representation to give voice to varied viewpoints, histories and realities not commonly featured within academic research and facilitating research processes that offer peoples marginally represented the opportunity to speak for themselves (Chilisa, 2012; Spivak, 1999). Particularly, voice as political representation implores scholars who have been marginalized to use our insights from the margins to give voice to these silences. A key aspect of
voice in Because She Cares was representing the Narrators within the findings. I incorporated quoted material and poetic retelling alongside my interpretations to illustrate that my interpretations are grounded in their sensemaking of their work. Another aspect of voice relevant from my epistemic stance was giving voice to knowing practices that are marginalized within the social sciences; hence my use of poetry and first-person voice within my writing. Lastly, a relational axiology required that I should give voice to findings in a manner accessible to the varied communities; this includes the use of arts-informed approaches as it can make research more accessible to lay audiences, allowing them to contribute their voices to the topical conversation.

Co-knowing recognizes participants as central to our research such that it shapes our methodological approaches and interpretations. D. Soyini Madison (2008) suggested that the people that we interview should hold primacy in our sourcing of knowledge, with our interpretations centred around their experiences and sensemaking of them through narrativization. As such, I strived to transparently illustrate the co-knowing process emerging amongst the Narrators and myself. I used narrative methods such as oral narrative and poetic interpretation and representation that positioned the Narrators as the originating source of knowledge from which my interpretations derived. I incorporated a workshopping process where I shared preliminary findings with the Narrators to better assure that the poetic retelling represented their sensemaking of HIV-related work. Sharing preliminary findings can better assure the credibility of interpretations (Lincoln, 1995); however, my intent was not simply to assure their trustworthiness. Instead, it was a relational practice that recognized that these poetic retellings were the Narrators stories; my interpretations derived from their teachings. I also wanted to represent the poems as oral knowledge that was shared with me; hence, the use of the
term “retelling”: it recognizes that I am not the original source of their creation and that these poetic interpretations originated from the Narrators’ story-telling. Treating narratives as knowledge sources, similar to other literary sources strives to mitigate the appropriation of knowledge that comes from conducting research (Chilisa, 2012).

Positionality requires me to recognize the social positioning which the Narrator and I may bring into the research relationship, and that these positionings can be both subjectively or socially constructed. Thus, I was mindful of the various ways which my positioning — African descendant, Jamaican Canadian, cisgender female, Ph.D. student, academic, social worker, HIV researcher, a former employee in the HIV sector, a co-worker in the response — could shape and shift the research dialogue, and my interpretive reflections. I was also mindful of geographies of power in its dominant (power-over), agential (power-within) and relational (power-with) forms as it operated within research contexts. As such, I tried to create a research space where these agential and relational forms of power could be invoked. For instance, workshopping the poems actively engaged the Narrators in representation and dissemination processes, and fostered a sense of ownership in the knowledge being generated. Prolonged engagement with the Narrators, and continued conversations with them in ways they preferred also recognize that they facilitated my learning. Positionality also required me to recognize my place in the academy and what it means to be *Black presenting* which is separate from *Black representing*. For me, Black presenting is a racialized performative, a by-product of colonialism and its hierarchical racial classifications; yet Black representing can reclaim a marginalized positionality that *needs to be represented* in privileged spaces, particularly in HIV research and schools of Social Work, where peoples of African descent are overly represented as research subjects, but minimally as knowledge producers.
While research consent processes are attentive to potential individual harms, relationality attends to collective benefits and harms as well. As such, I strived to assure that my representation of study findings did not paint the Narrators in a negative light. For instance, adverse experiences of living with HIV or of being racialized could construct African women living with HIV as victims, so I was also attentive to illustrating agential acts where the Narrators made sense of these constructions and strived to resist them. I also contextualized these adverse experiences referencing the broader social systems at play that “victimize” African women living with HIV. I also showcased narratives that represented varied experiences of HIV-related work. The narrative representation practices strive to see African women living with HIV from their viewpoint, recognizing broader social constructions articulated in individual work stories, honouring agential practices as they are narrativized, and illustrating diverse stories of work in varied local contexts. Interpretations viewed from the Narrators standpoint aimed to highlight the complexities of employment in HIV responses and to challenge dominant, universalized constructions of African women living with HIV.

Research from a decolonizing viewpoint is expected to be impactful for communities directly implicated and engaged in the research. I opted to represent findings such that they had a catalytic impact. For instance, I used creative methodologies not commonly utilized in academia to challenge authoritative stances of knowledge in the academy. Even in using creative approaches, I challenged the authoritative stances made by artists such as Jane Piirto (2002) who presume arts-informed research should be conducted by people who are recognized for their artistic craft as assessed by an authoritative body. However, this elitist notion seems derivative of the artistic exceptionalism that emerged in the Enlightenment era. Instead, I positioned the use of poetry in this thesis as a way of being and thinking artfully that deserved as much recognition
as the artisan craft. I agree with Carl Leggo’s (2008) assessment of goodness in arts-informed research: it should consider what the art does rather than who does it. If it evokes emotions, provokes action, offers reflections, and encourages dialogue, its goodness is assessed by its catalytic function rather than researcher’s credentials as an “artist”.

When using a relational axiology, we often speak of care in relation to others, but I think it is imperative to also consider self-care. Perhaps because of the aims of this research, I was acutely aware that a relational regard often makes us consider the “we” before the “me”, yet that perspective ill-considers that we need to care for ourselves to be with others; we need to consider what the work is doing to us emotionally, physically and spiritually in order for us to contribute meaningfully. I cannot say I was always mindful of self-care; in conducting my doctoral research, I put myself into situations where I heard painful stories and attended to the care needs of the Narrators, but not my own. In some cases, I was required to hold stories that implicated me as a researcher, “peer”, current employee and potential employer in the HIV sector, yet I had no place to share them. Not even with my supervisor because as an employer in the HIV sector she was implicated as well.

Interestingly, it was that reciprocal regard that the Narrators had for me that fostered my own self-caring. For instance, the Narrators were quite resourceful at creating off-tape moments that allowed a collective caring space. In these moments, we would talk about what the narrative experience was doing to us, and how we were experiencing it. At first, I questioned if this was the place for me to laugh, cry, rage, or reflect on what I experienced. Yet, in doing so, I recognized that we both had an equitable regard for each other’s feelings. My reflective journaling allowed me to express these tensions that I found self-caring. And when emotive tensions shaped my analysis, I would also share these moments with you, for I felt it fruitful for
you to know that the emotive moments I experienced in bearing witness also shaped my interpretation.

Self-care acknowledges humility for it recognizes our self in relation to others. Humility requires me to acknowledge that I am just one member of this conversation on HIV-related employment as a caring practice. And that my ways of knowing are shaped by other knowers, including the women whom I interviewed. Thus, I write this thesis as a reteller of the stories as they were told to me, but also as an interpreter of them. This does not shirk my responsibilities as a social science academic. On the contrary, it recognizes knowledge generation as a continuing dialogue where all interested parties participate in its production. Including researchers. Including participants. Including community. Thus, I represent this research as the continuation of a conversation, grounded in my relationships with my co-workers, many of whom are African women living with HIV who work in HIV responses. But I hope this dialogue will continue after this study ends with other knowers: academics, AASO representatives, employers, people living with HIV, and peoples of African descent.

Is It Moral? Moral Implications of Research with, for and by Peoples of African Descent

Conducting research using a decolonizing, transnational feminist framework required me to be mindful of the ethical tensions and moral implications of conducting doctoral research with and for African women living with HIV. While research with human participants demands ethical conduct as outlined by research ethics boards in academic institutions, research using a decolonizing, anti-colonial, transnational feminist framework also has to consider research as a moral compact amongst all parties involved in the research exchange (Maiter, Simich, Jacobson, & Wise, 2008). This moral compact recognizes research as relational: centred on human relations and constitutive of social relations within broader society. This moral compact recognizes the
ethics of reciprocity, or our responsibilities to honour our relationship with communities with which we do research, producing knowledge that recognizes their contribution and is of benefit to them (Wilson, 2008). As I reflected on the relational axiology that framed my moral conduct, I also identify some of the tensions that can arise when conducting doctoral research with, for and by peoples of African descent using a decolonizing, anti-colonial, and transnational feminist stances. To illustrate these tensions, I highlight four that were particularly relevant to the Because She Cares study: the moral implications and tensions of positionality, voice, relational knowing, and beneficence.

**Moral implications of insider-outsider positionality.** As noted earlier in this chapter, positionality required me to recognize the dynamic, relational exchange that was contingent on the research context and its interpersonal and broader social relations. Part of this relational exchange included the political positioning of insider-outsider positionality, where representing myself as an academic of African descent (Black representing) could serve as beneficial to peoples of African descent given our marginal representation in HIV research and Canadian schools of Social Work. In reflecting on the moral implications of relational positioning, however, I noted how this insider-outsider positioning as a political stance required me to be attentive to dominant, agential and collective nature of power and its relational accountabilities.

For instance, one narrator noted that as an HIV-negative woman, *I did not know* the hardship of working while HIV-positive. I noted how much she emphasized hardship in her work story, yet this hardship also intersected with her African homeland nativity, being a newcomer to Canada, and living in low-income circumstances in contrast to my Canadian nativity, Western upbringing and middle-class socioeconomic status. In her narrativization of hardship, she emphasized our differential social positionings and its power relations; her story illustrated
national, class, and HIV-related social locations as articulated within the narrated experience (i.e., narratives of work and HIV) and the narrative experience (i.e., her narrativization of her work to me, a Ph.D. student). And yet, at the end of the interview, she emphasized my relational responsibilities as an African descendant insider who is also an academic. As a “Black woman with a Ph.D.”, I should let other researchers know about her hardship. What I recognized is that despite the broader power relations that placed her in a position of hardship, and myself in a position of privilege, she exercised agential and collective power: tasking me to share her story such that it could be beneficial to other women of African descent.

While the political imperative of an insider-outsider stance and relational responsibilities are commonly discussed in research using decolonizing, anti-colonial and transnational feminist perspectives given the praxis, social justice oriented nature of these theoretical stances, I also recognized the moral implications of such positionings, in that as an academic of African descent, who was also a worker in Canadian HIV responses and known amongst ACB communities impacted by HIV, I was held more responsible than a researcher who did not share ethnoracial or work commonalities. In a sense, my insider-outsider status as an academic had become more than a social positioning, it was another working role for me to perform, a role integrally tied to my positioning as a racialized worker in the Canadian HIV sector. Though not the same positioning as the women I interviewed, there were parallels, such as putting our responsibilities to the “we” as paramount. I constantly wondered, was I taking on too much responsibility?

I also reflected on this notion of catalytic responsibility — that this research would make change — given it was a doctoral research study. Ph.D. research is not typically well-positioned to change organizational or governmental policies. Though I had buy-in from some ethnoracial
AASOs, the systemic nature of some of the concerns brought forth in this study — sexism, racism, ableism, xenophobia, HIV-related oppressions — operated within multiple local contexts of HIV responses and broader employment and economic systems. Yes, I could share the stories of women, but would that be enough to fulfil the tasks assigned to me?

In reflecting on the moral implications of insider-outsider positionality, I began to recognize that what some the Narrators were tasking me to do, was not my work alone. As Paulo Freire (1970/1996) advises, the transformative work of social change should involve the people for whom the change is intended. His notion of praxis included the involement of people with lived experience of the phenomenon, for it is they who should direct the reflection and action that reshaped their reality. As such, I worked with the Narrators to share research findings such that the findings could generate community reflection and action. Notably, we felt it best to create knowledge dissemination activities outside of my doctoral study, so that ACB community members could have greater involvement in knowledge sharing and mobilization. Even if praxis, — "reflection and action directed at the structures to be transformed” (Friere, 1970/1996, p. 107), begins as conversations amongst peoples of African descent — as people living with HIV, allied, and members of ACB communities impacted by HIV — that can perhaps generate concrete actions that we, in our varied positionings as workers in HIV responses, can enact.

**Moral implications of voice.** Research using decolonizing, anti-colonial and transnational feminist stances often promote multi-vocality, where multiple knowing perspectives are represented within research findings. Yet, multi-vocality can still reify knowledge hierarchies, where the interpreter’s voice overpowers that of the originating narrator, given academic voices preeminence within knowledge generation. Even in representing participants’ narratives passages
verbatim as their “voices” may mask the level of interpretation that determines what passages get presented and which ones do not; yet, these interpretive decision shape what is vocalized.

Particularly, my use of poetic representation begs the question: whose voice are we hearing? Though the poems are directly drawn from narrative passages of the Narrators, and I am mindful of using their own words, in selecting passages that resonate with me, I am making interpretive decision, including decisions on poetic orchestration — arrangements of narratives for emphasis and lyricism — that could potentially alter what the Narrator originally voiced.

There may be narrative details lost in poetic orchestration: a sentence removed or repositioned for poetic emphasis which consequently reshapes meaning. Workshopping poems strived to address these substantive concerns; the Narrators authenticate poetic retellings to assure it resonated with their sensemaking of their work. Narrators also pointed out that five-minute retelling could amplified specific reflections of their work that a three-plus hour narrative may not do. Yet, in these creative decisions I am also vocalizing my interpretative choice: what narrative passages resonated for me. Calling the poems, poetic retellings, may allow some transparency to the poetic representation process, but the tensions of interpretive choices when poetically retelling another persons’ story is not easily resolvable.

Generating knowledge within a doctoral research study can also amplify academic voices: its’ communicative practices, value systems, and preferred ways of transmitting knowledge. While unstructured knowledge gathering gave participants greater agential power in telling their stories, such story-telling is still constituted within academic contexts and its constraints. Although I have hundreds of pages of narrative texts from which to draw my interpretations, the doctoral research processes — research questions, thesis requirements, word limits — delimited how much of the participants’ voice is presented within my thesis. While I also used sociolinguistic
methods to better represent what participants communicated verbally and non-verbally, as an academic product, I am performing to academic audiences: written instead of orally performed, centred around the plot of a research question, and representative of the scholarly text required for a Ph.D. in the social sciences.

**Moral implications of co-knowing.** I strived to recognize knowledge generation as a relational process, crediting the Narrators and their narrative sensemaking as foundational to my interpretations. However, with relational knowledge comes the tensions of ownership: if the Narrator and I disagree with my interpretation how do we reach consensus? For instance, in sharing my preliminary interpretations during the workshopping process, I found that what I had interpreted in the Narrators’ stories of work, and represented in poetic retellings, they may not see the same way. Sometimes the change was a misunderstanding of wording or context that require clarification and minimal revision. In other cases, the Narrator wanted to retell their work stories in ways that substantially differed from the original narrativization.

For example, one Narrator seeing that her previous narrative was too critical of her Canadian AASO work experiences, added another stanza that changed the meaning of her poetic retelling from a critique to a vindication of capacity building in HIV-related work. When I asked about this alteration, she credited the change to her present working life; she was pursuing employment in a different sector that built upon her HIV-related work experiences. She desired to retell her poem to affirm her present working life, not realized when gathering her original narrative. While we made these changes to that particular poem, I also talked about the limits of what we could change: we could use poetic retellings to reflect her experiences of work and contextualize my interpretations in the broad context work and HIV, but I could not re-narrativize her work story. I could change words, but I cannot change her experiences. This got
us talking about what her work stories convey, critiques of HIV-related work keeping her underemployed, but that the knowledge gleaned from it led to a different vocational direction for her. Consequently, my interpretations strive to unpack these complexities, particularly how her critique illustrated neoliberalism in operation: dismantling of social services and cuts to funding contributing to limited employment opportunity in the Ontario HIV sector requiring some African women living with HIV to seek work elsewhere. What the workshopping processes illustrated was the static representation of poetic retellings, and yet the Narrators working lives were dynamically storied. As such, I recognized the contingent nature of poetic retellings that the workshopping process did not fully allow.

**Moral implications of impact.** In reflecting on the moral implications of impact, I also identified its interconnections to positionality, voice, beneficence and maleficence and resulting tensions. For instance, the catalytical impact of insider-outside positionality and multi-vocality as well as the risk: what may seem beneficial — using performance narrative as culturally responsive knowing practices in HIV research — could come with personal risks. For instance, representing the Narrators’ voices could inadvertently disclose them. Some the Narrators used their local languages or parables in their narratives that were particular to their homelands. Other Narrators shared homeland stories of HIV-related work. Perhaps because of our co-knowing relationship, they felt empowered to promote homeland perspectives of HIV-related work underrepresented in Canadian research yet, I worried if this representation could reveal who there were.

Other Narrators considered the collective benefits of sharing their story were worth personal risks of being identified. For instance, the Narrators who worked in mainstream agencies were at greater risk of being identified given the employment of women of African descent within
mainstream AASOs was not as common as being employed in ethnoracial organizations. Yet, the Narrators believed that sharing these stories could have collective benefit for other African women living with HIV who desire to work in mainstream organizations. The catalytical impacts of integrating homeland knowledges, languages, and experiences within a Canadian HIV research study were insurmountable, they promoted the multi-vocality of transnational feminist thought and could disrupt the dominance of Euro-Western (English) language within this study (González y González & Lincoln, 2006). Sharing unique narratives of work in HIV responses could also benefit African women unaware of these experiences. Yet, I worried if representing multi-vocality and unique experiences of HIV and work could come at some risks to Narrators.

In these tensions I found that protocols of ethical research conduct can guide our decision making as a researcher; yet, did not necessarily consider the tensions of catalytical impacts and its potential harms. Ongoing consent involved speaking openly with Narrators about benefits and harms over the course of the research relationship; we also weighed personal benefits and harms with collective ones. While I advised on ways that research conduct could mitigate these harms, I also was guided by the Narrators’ understandings of what they considered harmful. Some Narrators (but not all) identified with the potential benefits of sharing their stories as they were narrativized. Some Narrators (but not all) would rather omit passages, or poems that they believed could pose personal risks of disclosure. As such, I worked with the Narrators’ one-on-one to represent their narratives in ways that felt most safe to them. Sometimes this required rewriting poetic retellings such that the originating message was maintained, but some features were fictionalized. Additionally, where the message of the poem resonated, yet could inadvertently disclose, I used only passages of the poem in my thesis.
Looking at the catalytical impact of sharing these stories, I also considered the broader benefits and harms. How might these poetic retellings resonate with other audiences? Could their reception be harmful to peoples of African descent or people living with HIV? Kenneth Plummer (2001) spoke of “interpretive communities” (p. 43) or audiences who bear witness to our stories. Interpretive communities hear stories in particular ways based on personal experiences, cultural histories, the context of telling, and the interactive context (Plummer, 2001). Significant others — for example, peoples of African descent living with HIV with shared or similar experiences — may interpret the stories in a manner complementary to the message the Narrator or I intended. But what about others audience whose interpretation may constitute social perceptions, assumptions, and prejudices of peoples of African descent, immigrant women or people living with HIV? Meaning is constituted with the personal, cultural, experiential, social, temporal and historical contexts in which we are embedded and engaged. I was mindful that the stories that resonated with me might not resonate in the same way with audience members from different social locations.

In these individual and collective concerns of doing harm, I have engaged in conversations with ACB community members — first the Narrators and now with other ACB community members who work in Canadian HIV responses — to devise knowledge sharing for the Because She Cares Study that can be of benefit to ACB communities who work in HIV responses in Canada. Part of this work is devising knowledge sharing strategies that first test out these poems with ACB community members before sharing them with general audiences as well as selectively choosing which poems to share. While we are strategic, we also realize that despite our best intentions there is only so much we can control. Poems can be shared. Performances recorded. We cannot fully control the interpretive communities who may purview this work. While
knowledge generation guided by decolonizing, anti-colonial and transnational feminist perspectives should aim for impactful research, such as sharing work stories of African women living with HIV to generate conversations which may lead to action, impactful research cannot fully control the potential harms of the message if it is interpreted or received by audiences from different viewpoints.

I also grapple with aims of catalytical impact difficult to realize. Though we are co-knowers, the Narrators and myself, will the impacts of this research be mutually beneficial? I consider this as I represent the Narrators as co-knowers in a piece of academic work bestowing me with a socially prestigious degree. I reflect on this as I present at conferences, produce book chapters, and write peer-reviewed articles. Though creative works will have the Narrators as the co-authors, will listing their pseudonyms represent their co-authorship, or subalter their ownership? While this study has fostered conversations about culturally responsive methodologies in HIV research with, for and by peoples of African descent, I question if I am capitalizing on the “by”: an African descendant scholar using culturally responsive methodologies at a time when Social Work as a discipline is striving to decolonize its own mind and reaffirm that Black lives matter.

Bagele Chilisa (2012) offered reciprocal appropriation as a respectful practice where the benefits amongst the researcher and the communities for whom the research is intended are mutual. Yet, beneficence may not occur in the same degree. I consider this as I reflect on the opportunities that some of the Narrators hope the study will enact: improvements to HIV-related employment, changes in their workplaces, and greater job opportunities in Canada. Reciprocal appropriation from a decolonizing perspective also demands transparency. For the Because She Cares study, I have been transparent about opportunities this study can yield. I have
also discussed with participants how to continue our working relationship beyond my Ph.D. Consequently, transparency considers the relational space of an African descendant scholar working with communities of African descent; the opportunities bestowed to the scholar may position them differentially as an outsider-within.

I note the moral implications of research to acknowledge that even research with the best intentions of decolonizing knowing is constituted within the colonial relations of academic knowledge generation, and the broader relations of Euro-Western supremacy that operate in positionality, voice, co-knowing and relational impact. More pointedly, I want to be transparent about the tensions of using critical epistemological frameworks committed to social change as transnational feminist, anti-colonial, and decolonizing knowers are still working against the dominant knowing systems that are not as critical as well as resistant to change. That does not mean we should not strive to decolonize knowledge generation or promote transnational feminist or anti-colonial theorizing; nevertheless, we need to grapple with the tensions of conducting such research, for I believe within these epistemological tensions we can better our own practice as decolonizing knowers. Furthermore, if enough of us do this grappling, we can begin to make change.

Is It Participatory? Relationality of Participative Knowledge Generation

Throughout the Because She Cares study, I engaged with the community at various stages: I gathered advice from researchers and advocates of African descent with lived experience participating in qualitative research; gauged the interest of the study with ACB AASOs; and invited the Narrators to actively participate in the research process. But was this “participatory”. Well… no. And yes. Given the framework of community-based participatory research (CBPR), to actively engage the community at all stages of the research and foster equitable contribution
(Israel, Schulz, Parker, & Becker, 1998), I would say no. Even when some of the Narrators themselves asked me if I consider this study “community-based research” or “participatory”, my first instinct was to say no. However, one of the Narrators, who had worked on community-based participatory research projects, challenged my dismissal of its CBPRness. According to her, she has rarely as a research participant been given the opportunity to actively respond and shape research findings, advise on its dissemination, or have her narrative quotes (in this case poetically retellings) given back to her. Moreover, she never had the opportunity to call the stories she shared as a research participant, her OWN stories. And her critique made me pause for thought. How often do we as community researchers actively engage study participants in participating in the generation of knowledge founded on the narratives they shared with us? And when we do engage participants in member checking or verification of preliminary research findings, how often do we dialogue with them, as fellow knowers who can contribute to our interpretive process?

A key part of community-based participatory research is intent: what are your intentions to actively engage the communities for whom the research has an impact? Moreover, CBPR is not just about greater involvement but meaningful involvement: do the ways in which community members engage have meaning for them? Lastly, CBPR recognizes communities as capacity builders, and also as knowledge contributors. Though I did not intend to use a CBPR framework in the design of the study, many of its tenets — involving the community in theory-making, building my capacity through community engagement, developing knowledge that fosters community action — were embedded within the study design (Minkler, 2005). Lastly, participatory knowledge generational is often relational. Because She Cares incorporated decolonizing, anti-colonial and transnational feminist paradigms that guided its relational
ontology which in turn was reflected in its methodologies and method. Relationality is also my way of being in the world. Many locals ontologies of people of African descent are relational (Chilisa, 2012). Including my own. As such, I felt a communitarian imperative to learn from participants, actively engage them, and open up space for their participation. This communitarian imperative respects our relationships as co-knowers, as co-workers in HIV responses, and as peoples of African descent.
Chapter 6: What I Learned from the Narrators: HIV-Related Work as HIV Caring Work (Findings)

In this chapter, I share what I learned from the Narrators, what is often called the findings. What I found in the Narrators’ sensemaking of HIV-related work were these intersecting cultural and agential narratives of how work should and could be caring work for African women living with HIV (i.e., HIV caring work).

All the Narrators identify a continental African country as their land of origin or what I have called their homeland with various nation-states in sub-Saharan Africa represented. Their pathways into Canada varied as well: arriving in Canada as immigrants, undocumented persons, or refugees; coming directly to Canada from their homeland or migrating through other nation-states prior to their Canadian arrival. Engagement in HIV response activities ranged from three to over twenty years: some Narrators begun their involvement prior to coming to Canada, others became newly engaged to HIV response activities upon their arrival. The Narrators also had considerable employment experience, not just in HIV sectors, but in other sectors as well; experience obtained in their homeland and in Canada, employment prior to their diagnosis and after. I share these demographics to illustrate that the women I spoke to did not have this uniform, singular story of the African newcomer, re-entering the workforce post-HIV diagnosis or post-migration or pursing HIV-related employment. Their “choices” of HIV-related employment was as varied as they were. To give back. To get a job. To get experience. To get “Canadian” experience. To employ their experiential knowledge. To apply their vocational skills. To utilize their education. To obtain an income. To fulfil a passion.

To illustrate how the Narrators conceptualized their HIV-related work as HIV caring work, I would like to share five of their stories:

- Anna’s story of HIV caring work as vocal work
- Norma’s story of HIV caring work as a “calling.”
- Naomi’s story of HIV caring work as (un)supportive work
- Nadira’s story of HIV caring work as “successful” work
- Miriam’s story of HIV caring work as emotional work

I use the metaphor of quilting for my approach to finding the Narrators’ stories: each Narrator offered their own distinct story of HIV caring work that when read together convey common themes running through all the narratives: the possibilities and challenges of HIV caring work for African women living with HIV as women who are employed in the Canadian HIV sector and translocally embedded and engaged in other locales as well.

In this chapter, I represent each Narrator’s stories as a subsection: I present what I learned from each person followed by a discussion specific to the Narrator’s story. In the discussion chapter that follows, I discuss what each Narrator can teach us about HIV caring followed by what their stories collectively teach us about HIV-related work as translocal HIV caring work. I introduce each narrator within their respective sections along with their work histories and experiences of work as they wished to share them.
“When You Come Here You Just... Stay SILENT”: Anna’s Story of HIV Caring Work as Vocal Work

After six months of living in Canada
Something happened.
I think because of the change in environment.
Or, I missed my family.
Kept to myself, for six months.
I didn’t want to go anywhere.
I didn’t want to go to any AIDS service organization.
I didn’t want to volunteer.
I just wanted to cut myself off from the HIV field
Because like I said.
When I came here.
It was a different kind of environment.
It wasn’t the same here
[breath/pause] I wasn’t the same here

Advocacy is different back home

Back home, I was VOCAL.
I would go places and fight for change.
People back home encouraged me to advocate for myself.
As a person living with HIV
I REFUSED to stay silent.
If I noticed a gap in services
Or didn’t receive the treatment I needed
I would SPEAK UP.
And there were others who mentored me, supported me
Who taught me
How to advocate for myself.

Being involved in the movement back home
[breath/pause] It made me feel... GOOD.
Good that I achieved something
That I was making A DIFFERENCE.

When I came to Canada
I was no longer vocal.
Yes, being in Canada can be a good thing.
There is healthcare and everything else.
But I was no longer SPEAKING OUT!
It wasn’t just me alone
Other African women. They stopped speaking out as well.
When you come here you just … stay silent.
The advocacy, all that energy
Where do we take that?

At my ASO
I see people from my homeland
Who used to do grassroots advocacy alongside me.
Sometimes we just sit and chat.
“Do you remember what we used to do?”
“Do you remember the changes we made?”
And we all agree
We have changed.
Once we came to Canada, WE became silenced.

Back home,
We were ACTIVISTS.
People living with HIV
We advocated for each other.
IF ONE OF US
Have this bad experience in THE hospital
Couldn’t get HIV medication.
Got sick
Was stigmatized
WE ALL put our heads together
To see how we could
Take care of each other
Support each other
Advocate for change.
We would ensure that the mistreatment of one person
Would not happen to someone else.
MY problems were OUR problems.
Because if it could happen to ONE OF US, it could happen to ANY OF US.
But in Canada
One woman’s problems are HER problems

*If she*
Has a bad experience with a doctor
Problems with social services
Is sick
Stigmatized
Needs advocacy
She will not go to her HIV-positive peers who are clients
She will go to her ASO support worker.
IT’S THEIR JOB
To advocate for her.
Will she advocate for herself?
No.
As a client
*She will not.*
As African women living with HIV
*We cannot.*
And if we try to advocate ... for ourselves
We are made to feel *powerless.*

I think as African women
WE NEED TO speak for ourselves
WE NEED TO do something
WE NEED TO be activists.
Waiting for a support worker to speak on our behalf
That is not the African way.
Because back home
If we wanted something we didn’t wait.
We would advocate
We would work together as a COLLECTIVE... as a GROUP.
We took care of each other.
Back home, we would get together.
Make placards
March to parliament
Show up on TV
Call the media.
We would shout
“This is what we want.
As HIV-positive people.
This is what we want!”

In Canada,
Who will march to parliament?
Show their face on TV?
Shout?
Who wants to do that now?
Why don’t we do it now?

Sometimes I talk to other Africans
Who talk about what we did not have back home
But can get in Canada.
There is Medication. Health care. Welfare.
They look around and say
“Life in Canada is good”.
Other Africans look at what is offered in Canada
But not at what we don’t have here
Or what we lost in coming here.

Life is good in Canada?
Is it? Is it so good?
There still is a lot worth fighting for
Life could be BETTER.

How can we
As Africans
Fight for our rights within this country?
Where do we go?
Who do we go to?
Who will listen?
How do we start?
I don’t know. Do you?
It is not just US who have been silenced:
Our Caribbean sisters ...silenced.
Our other Black sisters ...silenced.
Our Latina sisters ...silenced.
Our South Asian sisters ...silenced.
Our Asian sisters ...silenced.
But if we put our voices together
We could be LOUD!

We all came to Canada. And then silence.
But I believe
WE STILL HAVE our voices.
WE STILL HAVE that fight within us.
WE STILL ARE ACTIVISTS.
“WE WILL NOT BE SILENCED!”

“We all came to Canada ... then silence”, Anna

In listening to Anna’s stories of HIV-related work, what resonated was her sensemaking of its vocal work. Her vocal work had been monumental to her personal and professional growth as a person living with HIV; moreover, she derived care and support from her engagement in HIV responses which she decided to “give back” through her activist “voice”. Notably, her vocal work in HIV responses shaped her senses of belonging in the locales within which she engaged.

In Anna’s homeland, Anna’s voice was “loud” as a woman living with HIV whose active participation in civil societies made a meaningful contribution to local response activities. In Canada, however, Anna’s found her voice “silenced” and her participation constrained by professional expectations of engagement as an employee within an AIDS service or allied organization (AASO), and social expectations of how Anna should engage as a racialized immigrant living with HIV.

To understand how Anna made meaning of her AASO employment as “vocal” work, I narratively journeyed with her across time and place. It was in her re-membering and placemaking her homelands ways of caring vis-a-vis HIV-related work where Anna rekindled
what made this work meaningful engagement and how her work fostered a sense of community with her transnational “sisters” in her homeland and in Canada. What Anna’s story of HIV-related work as vocal work illustrated were the locales within which she could give voice to her activism; the political and social contexts within which her work took place shaped how “loud” her activist voice could be. In heeding the call of her activist voice, Anna narrativizes how HIV caring work interconnected to African women’s opportunities to vocalize their activism.

Finding back home voice(s) of HIV activism

Back home, I was VOCAL.
I would go places and fight for change.
People back home encouraged me to advocate for myself.
As a person living with HIV
I REFUSED to stay silent.
If I noticed a gap in services
Or didn’t receive the treatment I needed
I would SPEAK UP.
And there were others who mentored me, supported me
Who taught me
How to advocate for myself.

Passage from “We all came to Canada ... then silence”, Anna

Anna had engaged in HIV responses for several years, many of them in her homeland. Prior to her diagnosis, she had planned to work in a different sector. Once she became engaged in HIV responses in her homeland — first as a recipient of support services, later as a volunteer, spokesperson, educator and activist — she moved towards employment in the HIV sector. She liked the community-mindedness of HIV-related work and its relational nature. She appreciated that she did not have to divide her caregiver self from her care recipient self when working on homeland response activities. She also valued giving back to the community organization that offered her substantial support when she was first diagnosed. The reciprocal nature of caring in her homeland’s HIV responses is what attracted her to pursue a career in the HIV sector.
What also attracted her was the encouragement of her activist engagement. Anna's activism first came from her experiences as a recipient of HIV services. Noticing gaps in service delivery as a woman living with HIV, she demanded women-centred care. With the mentorship of another person living with HIV, she created a program, which later became replicated in other AASOs:

And I told him. If we had a women’s group, it would be better. And he said, “Okay. So, you’re a woman. So, you can start a women’s group for HIV-positive women.” [Oh wow!] And I was like, “How do I do that?” “Okay, I’ll show you how.” So he mentored me [okay] and I started program that runs up to today. [Oh wow – So you founded it.] Yes. And, you know, it was a success. — Anna

Notable in Anna’s story was how civil society engagement in local HIV responses became reciprocated care responsibilities between Anna, local CBOs, and the state. In seeking self-care, Anna identified service gaps for an underserved demographic in her local CBO; with the mentorship and instrumental supports, she developed programming that served as a model for others. Her participation in her local CBO also gave her as a person living with HIV greater agency in how she wanted to engage in response activities. Governmental funding of civil society responses also provides a formalized infrastructure that allowed her and other people living with HIV to develop HIV-related programming. Anna’s homeland story of HIV-related work illustrated the interconnectedness between state and civil societies’ responsibilities of active participation, including the recognition and support of civil societies’ distinct roles in fostering the active participation of people living with HIV in response activities such as peer mentorship, capacity building, and independent governance (Kearns, 1995).
As reciprocated care, Anna’s active involvement in civil societies not only contribute to the HIV movement in her homeland, it also contributed to Anna’s self-care. Notably, Anna felt *GOOD, in doing good* vis-à-vis HIV-related work:

> Like, back home. We are used to *advocating* for better *healthcare*. You know, lots of stuff. You just advocate. And you know, you feel... *GOOD, that you achieved something, you know? — Anna*

Anna realized that the goodness of contributing to homeland HIV responses stemmed from making a substantive social change in her homeland such as advocating for better healthcare and assuring one’s advocacy as a person living with HIV were realized in society. As Anna became increasingly involved in local response activities, she realized reciprocating care with and for people living with HIV required *political engagement*: serving as a spokesperson, educating community members, marching to parliament. She also recognized that addressing injustices faced by people living with HIV in her homeland coincided with other social inequities — income disparities, experiences of intersecting oppression, availability of comprehensive health service. Through political participation, Anna was able to connect HIV-related mobilization to broader health care reform; political engagement vis-à-vis HIV-related work realized her social responsibilities to create a more just society (Onyx et al., 2012)

In her engagement in homeland HIV responses, as a service user and as a worker, Anna found her *activist voice*. That voice was initially tentative, hesitant. Yet through the caring mentorship of other people living with HIV, she gradually developed this voice. Moreover, her activist voice extended outside of HIV-related mobilization to broader social justice concerns in her community. In realizing her rights as a person living with HIV to engage in HIV response activities, Anna also responded to social responsibilities to advocate for the betterment of the
local communities to which she was embedded and engaged. This social betterment included political mobilization alongside other people living with HIV.

Back home,
We were ACTIVISTS.
People living with HIV
We advocated for each other.
IF ONE OF US
Have this bad experience in THE hospital
Couldn’t get HIV medication.
Got sick
Was stigmatized
WE ALL put our heads together
To see how we could
Take care of each other
Support each other
Advocate for change.
We would ensure that the mistreatment of one person
Would not happen to someone else.
MY problems were OUR problems.
Because if it could happen to ONE OF US, it could happen to ANY OF US.

Passage from “We came to Canada, then silence”, Anna

Anna’s story of HIV-related work also illuminated collective mobilization as realizing her cultural responsibilities of belonging as a person living with HIV and as an “African”. Noticeably in Anna’s narrative was a story of HIV-related work as “OUR” story, a communal story of “advocating for each other”, “taking care of each other”, “supporting each other”, as people living with HIV. Anna often spoke in we terms about her homeland HIV-related work: “We were ACTIVISTS”. “If ONE OF US…WE ALL put our heads together”. “MY problems were OUR problems.” The “we”-ness of Anna’s HIV-related work narrativized this moral responsibility to work together to address HIV that was illustrative of her local culture. Particularly, Anna understood her collective orientation as integral to her identities and senses of belonging as an African.
When I asked Anna to clarify if this collective-oriented approach to HIV response activities were common in her homeland, she spoke about this approach as being “African” ways of engagement:

Because back home. If you want something you go for it as a collective... group. Or you know - [I: Is that a <Homeland> thing? Or an Africa thing?] I think it’s most African. [okay] Yeah. — Anna

Anna’s approach to activism denoted what Alison Swartz & Christopher Colvin (2015) framed as an “African-ness of caring” (p. 142): civic engagement as cultural practices of communal belonging. In this African-ness of caring, HIV-related work becomes integral to one’s cultural identity as well as one’s social responsibility to care for other Africans (Swartz & Colvin, 2015). This understanding of activism as a communal responsibility echoed cultural precepts common in many African cultures, a relational axiology to care for each other as human beings (Chilisa, 2012). This relational axiology seemed to underlie the moral imperative of Anna’s political engagement — one must act in solidarity with others to address collective concerns that impact all (Metz, 2007). In her sensemaking of collectivist caring vis-à-vis HIV-related work, Anna emphasized the African ways of political engagement as both a social act and process: to work with one another as African peoples and as persons living with HIV, and to politically mobilize together in the address of HIV.

What resonated in Anna’s sensemaking of her HIV caring work as vocal work was the relevance of her homeland ways of caring for the communities to which she belonged, notably, African peoples living with HIV. Particularly, she had to narratively go back home — narrativizing her HIV-related work in her homeland, speaking about the local and broader African cultures of civic engagement — to re-member what her HIV-related work should embody: the social imperative to engage in HIV responses as people living with HIV, and the moral imperative of caring for others for whom she identified. In turn, these social and moral imperatives to care
coupled with the reciprocity of caring empowered Anna and other Africans living with HIV to advocate: not just for personal betterment, but for social betterment as well. In Anna’s sensemaking of HIV-related work as “African ways” of caring, there were no divisions between voluntary and paid work, HIV or broader social issues, individual or collective concerns. Anna’s back home narrative offered HIV caring work as elemental to active engagement: fostering the capacity of people living with HIV to be actively engaged, which in turn was reciprocated in their civic and political engagement. This active engagement in Anna’s homeland also embodied cultural precepts to care that made substantive change within one’s community.

The silencing of African activist voices in Canada

After six months of living in Canada
Something happened.
I think because of the change in environment.
Or, I missed my family.
Kept to myself, for six months.
I didn’t want to go anywhere.
I didn’t want to go to any AIDS service organization.
I didn’t want to volunteer.
I just wanted to cut myself off from the HIV field
Because like I said.
When I came here.
It was a different kind of environment.
It wasn’t the same here
[breath/pause] I wasn’t the same here

Passage from “We came to Canada, then silence”, Anna

In giving voice to her African activism, Anna also narrativized a Canadian silencing. In comparing what her activism used to be in her homeland, Anna also illustrated what it no longer was. Back home, Anna was quite vocal in her activist identity; in Canada, she found her activist nature was restrained. Notably, the political engagement visibly present in her homeland responses was relatively absent in her Canadian AASO employment.
Part of that silencing may have stemmed from the migration experience. Anna came to
Canada on her own, seeking asylum. As a newcomer to Canada, she initially had no family here
and was isolated from her support system. So instead of seeking supports in AASOs, she
retreated from them. However, as I listened to Anna narrativize her senses of belonging in
Canadian and African spaces, what became noticeable was Anna’s activist voice being silenced in
Canadian spaces. Anna’s silencing illuminated the politics of belonging for African women who are
employed in Canadian HIV-related work: the politics of professional belonging as social service
employees who must delineate social responsibilities as worker from their rights to be politically
engaged; and the politics of social belonging as racialized immigrant women living with HIV in
Canada whose social inclusion is constantly under question.

Silenced…as professional advocates

But in Canada
One woman’s problems are HER problems
If she
Has a bad experience with a doctor
Problems with social services
Is sick
Stigmatized
Needs advocacy
She will not go to her HIV-positive peers who are clients
She will go to her ASO support worker.
IT’S THEIR JOB
To advocate for her.
Will she advocate for herself?
No.
As a client
_She will not._
As African women living with HIV
_We cannot._
And if we try to advocate ... for ourselves
We are made to feel _powerless._

Passage from “We came to Canada, then silence”, Anna

In speaking of her Canadian employment in the HIV sector, Anna narrativized the professional silencing that has evolved as civil societies became increasingly responsible in delivering social welfare on behalf of the state. In Ontario, the current model of HIV community-based care is a partnership between the state, community organization, and the communities it serves; yet, Suzan Ilcan & Tayna Basok (2004) indicated that in the context of neoliberalism, civil society-state collaborations have become more one-sided, with CBOs becoming modes of state governance. For example, in Ontario, AASOs who receive provincial funding are “recommended” to align their response activities to the HIV Strategy supported by the Ministry of Health and Long-Term Care (Ontario Advisory Committee on HIV/AIDS (OACHA), 2017). Yet, these recommendations are often tied to government funding. While the initial aims of civil society-state collaborative models of HIV community-based care were for the government to provide material support while allowing for community agencies to provide flexible services congruent to community needs, this partnership may have also contributed to HIV response activities that align themselves more with government mandates. Consequently, AASOs have predominately shifted away from the political mobilization upon which they were founded.
As modes of state governance, AASOs have become bureaucratic — with formalized organizational structures and specific roles and responsibilities for workers living with HIV — to assure they can be perceived as socially responsible in fulfilling state mandates. Yet, this increasing bureaucratization has also contributed to the growing professionalization of service provision and inevitably, the depoliticization of AASOs (Cain, 1993; Cain et al., 2013). Notably, many transnational HIV activists have cautioned that the alignment of state and civil society responses to HIV are interconnected with the decline of oppositional political engagement in civil societies (Batliwala, 2012); as community organizations embodied the value systems of the governments they once rallied against, often to assure continuity of funding, civil societies have depoliticized their own responses to HIV (Lee et al., 2016).

The professionalization of AASOs has also shaped how people living with HIV engage in HIV responses as “service providers” and as “clients”. For instance, the professionalization of HIV-related work has fostered more formalized approaches to service delivery where the roles of volunteer and paid worker, service user and service provider are clearly delineated (Cain, 1993). Moreover, states policies that regulate advocacy have further depoliticized AASOs. For instance, the Canadian Revenue Agency’s (CRA) Political Activities Audit Program, initiated by the Federal Conservative government in 2012 and recently suspended by the Liberal government in 2017, restricted political activities to 10 per cent of a charitable organization’s resources with enhanced compliance mechanisms such as regular audits to regulate political advocacy (Parachin, 2016). This federal program has been credited with creating a pervasive advocacy “chill” where CBOs, including AASOs, substantially restricted their political advocacy for fear of audits and lost charitable status (Consultation Panel on the Political Activities of Charities, 2017). In this milieu, advocacy became a professionalized service that AASOs and its workers provide to ensure the
immediate care and well-being of individual clients, yet devoid of the collective mobilization that HIV community service once embodied. And Anna, working in this depoliticized environment, found that since coming to Canada, her role in HIV responses had morphed into that of professionalized advocate where she was primarily responsible in delivering health and social services to other people living with HIV, and no longer mobilizing around social injustice issues collectively experienced by people living with HIV.

Moreover, the morphing roles and responsibilities of HIV-related advocacy have stripped people living with HIV of their agential rights of care, including their rights to collectively and politically engage regardless of their roles in the response. Instead, the worker as professional advocate gains the voice of the response, and is responsible for “talk[ing] on behalf” of other people living with HIV:

Lori: So if you’re in a support group. A similar support group. And you told them the same thing. You’re in hospital, you felt stigmatized. What do you think would happen?

Anna: You know, we can do nothing. As clients. So I don’t know why they feel that way, but they don’t have any kind of say? You know? Even when they have problems with their doctors they come and say, "Oh Anna, I had a problem with my doctor. I’ve been trying to tell my doctor to change my medication for a long time." And I am like, “So you can speak out for yourself.” “No, I need you to come and talk on my behalf.” And I am like, “Okay no problem. I’ll come and talk on your behalf.” — Anna

As clients, we cannot. What resonated in Anna’s sensemaking of professionalized silencing, was the powerlessness of clients living with HIV. No longer feeling able to advocate for themselves in Canadian AASOs, clients depended on service providers, including service providers living with HIV, to speak for them. In turn, there was a collective silencing: the professionalized advocate may be able to speak on behalf of other people living with HIV, yet in serving as a professionalized advocate, people living with HIV were no longer collectively advocating for each other. Anna believed that people living with HIV accessing services in
Canada were bounded by these rules of inactive engagement: to submit to service provision rather
than being agents of their own self-care. And it was Anna’s job as a professional to advocate for
clients on behalf of the state, but not as a person living with HIV to advocate for other people living
with HIV.

As Anna spoke about her professionalized advocacy “on behalf” of clients, and how it
discouraged self-advocacy, I recognized how professionalization redefined rules of active
engagement amongst people living with HIV. Whose voices should be heard. While grassroots
engagement promoted the active involvement of all people living with HIV, professionalized
engagement shifted these responsibilities to the worker formally employed within AASOs. These
rules of engagement between the service provider and client countered the “African-ness” of
communal engagement Anna had experienced in her homeland, where, as a recipient of services
she was encouraged to advocate for herself and other people living with HIV. Regardless of
their working roles, people living with HIV mobilized together.

The depoliticization of HIV responses not only restrained who could advocate, but it also
restricted the parameters of advocacy. While Anna’s homeland activism positioned HIV epidemics as
symptomatic of broader social injustices including gender injustices, income disparities, and
limited social welfare, she found that in Canada, HIV response activities were primarily centred
on the biomedical aspects of HIV, and its prevention, treatment and care, less so on
interconnecting social issues. Yet this myopic approach to HIV intervention ran counter to
Anna’s human rights conceptualization of HIV-related care, where any social issues that
impacted people living HIV were interconnected and required address. Nonetheless, Anna’s
responsibilities as a professionalized advocate required her to apply this myopic lens to her
advocacy even if broader social justice approaches were desired or required.
In one case, Anna had a client whose children were apprehended by child welfare authorities. As she felt this issue was relevant to the well-being of her client, she approached various AASOs to advocate on the client’s behalf but was met with resistance. When she tried to go beyond her professional jurisdiction as a frontline worker, she was met with resistance within her agency. She explained to me that issues of child apprehension were an ongoing concern for women living with HIV but felt that many AASOs did little to address this systemic issue. This experience of not being able to advocate for her client as these concerns extended outside her agency’s mandate made her question if the professionalized advocacy espoused in Canadian AASOs really helped the clients she was supporting:

How many women, HIV-positive women have had their children taken? You know? As a service provider. I feel frustrated. At the same time I was like. If it was me because I’m a PHA [and a mother]. Yes, and I’m a mother. How what I feel if the same people, I say are there to help me, they’re funded to help me. They are not doing anything to support me and I just watch my kids going you know? But if this was in Africa, we’d knock on doors ((slamming hand on table)) we go to the media ((slamming hand on table)) we take this this this ((slamming hand on table)) YOU CANNOT TAKE THESE WOMEN’S KIDS! ((slamming hand on table)) Do you get me? [I get you.] Yeah. So now people just watch. Their kids are gone. — Anna

Anna’s anger and frustration were palpable. And in articulating that anger and frustration she recognized her multiple positionings in the response — as a woman, a person living with HIV, and activist — that were unable to speak on behalf of women living with HIV. But could have spoken as a worker in homeland responses. And so, I understood Anna’s professional silencing. And for me it was loud: it voiced her activist silencing in Canadian HIV responses and spoke of her frustration with professionalized HIV service provision.
Silenced… in Canada locale

When I came to Canada
I was no longer vocal.
Yes, being in Canada can be a good thing.
There is healthcare and everything else.
But I was no longer SPEAKING OUT!

It wasn’t just me alone
Other African women. They stopped speaking out as well.
When you come here you just … stay silent.
The advocacy, all that energy
Where do we take that?

Passage from “We came to Canada, then silence” Anna

Anna’s silencing also stemmed from feeling disconnected to Canada: its culture, values, and practices. The senses of communal belonging she narrativized when speaking of African locales, did not seem to extend to Canadian ones. Anna’s narratives of her homeland work openly expressed her psychic, culture, collective, conscious belonging as an African. Her homeland habitus — embodied cultural values and perceptions (K. Brickell & Datta, 2011) — were articulated in her re-memberings of homeland activism. However, this habitus did not extend to how she positioned herself in Canadian locales. Anna’s narratives of her Canadian work narrativized a geographic locale, a place where her body was located, but not her spirit. As Anna struggled to make sense of her silencing, Canada’s racialized and nationalized norms of political engagement were also implicated. According to Anna, Canadian locales were not an easy place to be politically engaged as an African woman living with HIV.

Anna found limited support in mobilizing on social causes such as housing, income security, and child welfare. At first, she suggested this limited social mobilization was due to people’s “comfortability” with Canadian welfare systems such as access to healthcare. Yet as she reflected upon her conversations with other African women who had also been homeland activists, she
questioned if that comfortability discouraged people from speaking up. She contemplated if this silencing was truly of their making, a choice to leave their activist voices back home, or if it was a social silencing that came from their positioning as African women in a Western country:

Anna: And some of the clients I know. We’ve come from Africa together. We’ve done grassroots advocacy together. You know? We’ve known each other before we migrated to Canada. So.

Lori: And how is that experience?

Anna: Umm (pause)

Lori: I just wonder, given what you said about grassroots advocacy in Canada. What happened in Canada in terms of advocacy and grassroots.

Anna: Yeah. Sometimes we sit and just chat. Like. You know. Do you remember this day? What we used to do? And stuff like that. And. And like the people that I talked to that are here. They all say we came to Canada and we’ve changed. You know. We changed.

*We changed.* What resonated with me was how she attributed this silencing to the Canadian locale. Notably how being in Canada had “changed” her. And had changed other African women activist as well. When I asked Anna why they couldn't collectively mobilize the way they did back home, what had changed, her response indicated that her senses of belonging in Canada were quite different from her homeland:

Anna: But we still have that in us. Like, we can fight. But I don’t know how. [Mmm] Hmm? [Mmm]. I know a few people that if we get together, we can (laughs) shake, but how do we (laughs)?

Lori: And have you thought about that? [huh?] Have you thought about shaking some trees?

Anna: Yes, but we ask ourselves that we are Africans. This is not our country [Okay. Okay.]

In denoting herself and other advocates, “as Africans”, she also denoted a them-ness: as Africans, Canada was not “our” country. In Canadian spaces, African activists did not feel empowered to actively engage in its betterment, perhaps because they did not feel that they
belonged. “This is not our country.” Anna gave voice to her activist silence in those five words: 

_This is not our country._ After several years. Living here. In Canada. Anna believed. Canada was not her place.

In listening to Anna’s narrative of vocal work, I became more thoughtful around the politics of belonging in Canada for African women living with HIV who are also activists. According to Nira Yuval-Davis (2006a), the possibilities of belonging could involve political projects that forge collectivities, promote collective values, practices, and beliefs or demonstrate shared visions, ideals or political aims. HIV-related activism as a caring practice is intertwined with the possibilities of belonging in the locales within which one is engaged; it can promote shared visions of realizing the rights of people living with HIV which in turn can foster senses of belonging in the locales within which one actively participates. However, these possibilities of belonging can only be realized if community members are made to feel like they belong in the locales within which they are civically or politically engaged (Yuval-Davis, 2007).

Anna’s questioning of how she could engage her African ways of activism in Canadian spaces interconnected to the politics of belonging as an African living in Canada. As John Crowley (2005) reminded me, establishing senses of belonging as immigrants is overtly and covertly policed. The politics of belonging in Canada exists as “the dirty work of boundary maintenance” (Crowley, 2005, p. 156) that unites or divide peoples within Canada as _Canadian_, or _not of this country_. As Canadian nativity represented the dominant norms of Canadian citizenship, Anna sensemaking of Canada not being her country articulated her social othering as an African. Furthermore, this social othering in the context of oppositional engagement can put African women living with HIV at further risk of social censure. This policing process can become self-governed such as moralized responses to political mobilization that shape how people actively
engage as “good” political citizens (Power, 2012). As such, political engagement that challenges the status quo could be interpreted as *dis-integration* — an oppositional challenging of the values in which Canadian society upholds — which could further position African women living with HIV as not of this country. As such, I wondered if this staying silent became a protective measure for Anna, a way to *integrate* (or more accurately *assimilate*) into Canadian society and mitigate the surveillance African women living with HIV experience as Canadian immigrants. So, I agreed with Anna. *She had been silenced.* As many other immigrants living with HIV have been silenced in Canadian spaces.

Anna’s questioning of her belonging as an African immigrant woman activist in Canada illustrated a larger existential question: how does one mobilize around social issues in a society that does not foster one’s belonging? As a professionalized worker living with HIV, Anna’s ways of activism, her *African ways* of activism, were constantly under question and disregarded by her professional counterparts. Accordingly, her approaches to HIV mobilization — making placards, marching to parliament, speaking to the media, being vocal — seemed to Anna as not the *Canadian way.* What Anna vocalized in her sensemaking of her professional and social silencing vis-à-vis HIV-related work were the *multiple boundaries of belonging* that confined the ways in which African women living with HIV could care as activists. Within neoliberal capitalist societies, HIV activism is put in its place: within the boundaries of professionalized HIV advocacy. As immigrants, African women are put in their place: as “migrants” who do not belong, yet should assimilate into Canadian society, and silence their homeland ways. African women living with HIV who are employees are put into their place as well: be silent in your activism unless professionally mandated or congruent with accepted modes of active engagement in Canada. The boundaries of belonging in Canadian spaces as an African woman
living with HIV demanded that Anna stays silent: uphold the status quo, respond to her professional mandate, self-govern her active engagement in accordance to Canadian norms.

“WE STILL HAVE our voices”: The subversive voices of quiet activism

It is not just US who have been silenced....
Our Caribbean sisters \[\text{silenced}\].
Our other Black sisters \[\text{silenced}\].
Our Latina sisters \[\text{silenced}\].
Our South Asian sisters \[\text{silenced}\].
Our Asian sisters \[\text{silenced}\].
But if we put our voices together
We could be LOUD!

We all came to Canada. And then silence.
But I believe
WE STILL HAVE our voices.
WE STILL HAVE that fight within us.
WE STILL ARE ACTIVISTS.
“WE WILL NOT BE SILENCED!”

Passage from “We came to Canada, then silence”, Anna

And yet Anna didn’t stay silent. In making sense of her silencing in Canadian spaces, she also re-found “voice”. Notably, she re-found collective voice: she emphasized her solitary alongside other women who were marginalized in Canada whom she calls “sisters”. Particularly, she re-found “community” amongst African, Caribbean and Black women living with HIV. She continued to engage her African ways of caring through everyday practices of informal advocacy. In speaking of how she supported her “sisters”, Anna offered subversive ways in which she and other marginalized women vocalized their collective advocacy in the Canadian context:

Anna: ...It’s there. Maybe in community. Maybe if someone is sick in the community. Or they pass away, or they have immigration problems. We get together as a community and we see how best we can to support them.

Lori: But, so there is still that [yes!]. Yeah.
Anna: Those like, “So Anna has this problem. So let’s meet and see how it goes.” - So we have that.

Though it was not the same mobilization activities that she engaged in back home, it incorporated similar communal practices of caring for others, what Marina Alvarez & Ginetta Candelario (2001) called quiet activism. In this quiet activism, Anna spoke of working with other African, Caribbean and Black women to address concerns that AASOs failed to resolve: taking in someone children, providing home care, addressing migration issues, or planning a funeral. They met amongst themselves and found ways to support each other, often providing support in a fashion that was very reminiscent of their homeland ways of collective caring: being each other’s family as they are so far away from them. This collective care extended outside of the geographies of "African ways" as African, Caribbean and Black peoples worked together to support each other. This re-found collectivity amongst African, Caribbean and Black peoples in Canadian spaces recognized common experiences of racialized silence and shared strategies of resilience (hooks, 2000). Anna reclaimed her collective caring ways alongside people with whom she had forged a sense of belonging in Canada. With her sisters, Anna reclaimed reciprocated and communal care. And in these acts of caring, she re-found her activist voice. It was subversive as it resisted the social silencing: the individualistic, depoliticized, disempowered and exclusionary practices of HIV-related work that Anna encountered in Canada.

The possibilities and challenges of realizing voice in HIV caring work. Anna taught me how to conceptualize voice in the context of HIV caring work. Anna found her voice through civic engagement in HIV response activities and political engagement on behalf of people living with HIV. Notably, her activism shaped her senses of belonging in the locales within which she engaged. In Anna’s homeland, her voice was “loud” as a woman living with HIV whose active participation in civil societies made a meaningful contribution to local
response activities. In Canada, however, Anna’s found her voice “silenced” and her participation constrained by professional expectations of engagement as an employee within an AASO, and social expectations of how Anna should engage as an immigrant living with HIV. Nonetheless, Anna re-found her voice through everyday practices of communal caring: working alongside African, Caribbean and Black “sisters”. What also resonated was Anna’s “silencing” as an activist. Notably, her silencing illustrated the politics of belonging as an African woman living with HIV in Canadian neoliberal society. The professionalization of work in the HIV sector bound Anna to neoliberal responsibilities of community government: to assure that people embedded in neoliberal societies engage in civic activities that realize the minimal social welfare state (Ilcan & Basok, 2004). In the context of community government, community organizations become responsibilized: increasingly obligated to fulfil state responsibility such as the delivery of social programs and services (Wakefield & Fleming, 2009). This responsibilization can consequently divert community organizations from engaging in the social justice oriented political engagement that realizes community members rights of citizenship (Ilcan & Basok, 2004). In this vein, the professionalization of AASO has become neoliberal projects that assure the devolution of HIV-related care from public service to civil societies; yet the consequences have been the diversion of Canadian civil society responses away from their grassroots origins.

Despite Anna’s neoliberal belonging as a professionalized worker, as an African newcomer in Canada, Anna’s belonging in Canadian spaces was not assured. Because of Anna’s positioning as an immigrant in a country that privileges Canadian nativity, Anna was implicitly reminded that Canada was not her country. These politics of belonging — integrating Canadian processes of professionalism and activism — became salient in Anna’s inability to express her “African ways” of HIV-related work grounded in grassroots activism and reciprocated care.
Despite the responsibilities and politics of belonging in neoliberal Canadian spaces, Anna re-found community through HIV-related work. Particularly, in aligning herself with other “sisters” she established a sense of belonging through everyday acts of caring. Pamela Herd & Madonna Harrington Meyer (2002) suggested that care work exists as civic engagement amongst women though it remains undervalued and under-recognized. Yet, I wonder if in its invisibility, in its “quietness” (M. Alvarez & Candelario, 2001) care work can sometimes allow African women living with HIV the opportunity to reclaim their cultural ways of being and belonging on their own terms, outside of the neoliberal professionalized responsibilities of their paid HIV-related work.

What Anna taught me from her story of HIV care work as vocal work is that voices of African women, silenced within neoliberal responsibilization and racialized politics of belonging, can become amplified within civic, social and political engagement alongside peoples with common experiences of marginalized silencing, and who share collective desire to reclaim their voices again vis-à-vis HIV-related work.
“When You Get Here You’re Encouraged More to Think of, What Your Calling Is.”: Norma’s Story of HIV Caring Work as a “Calling”

Naturally I am an empathetic person.
I do like to help and want to help.
That’s what I gravitated towards.

In my field of work back home.
I did not choose based on what I was feeling.
But it was the type of profession that was going to
Take me to the top.

So that’s what we strove for back home.
We STROVE for good grades
And
We STROVE for a good job.

But when you come to Canada
You are encouraged more
To think of
What your calling is.

And so I was like.
“\textit{I can do administrative work}
But I’m not \textit{ful-filled}.”
So I started to look for other work
That could fulfill MY CALLING

Someone suggested that I do career counselling.
At first I thought it would satisfy me

As someone who came here as an immigrant.
I was TOTALLY CON-FUSED.
I had NO CONCEPT of what a resume was.
I had no idea about the Canadian job market.
As a career counsellor
I ... wanted to hold people’s hands.
Gently say … “Do this”
Not. “YOU SHOULD DO THIS!”
I thought career counselling was about guiding someone.
But it wasn’t.
And it wasn’t gentle.
I discovered that career counselling was LIMITING.
And really cold.
It didn’t feel empathetic at all.
It was not what I thought it was in my head.

Yea so I struggled with that.

Then I decided to go back to school again
What I wanted to do, my LOVE is politics.
I come from a family of activists
So it was almost like a calling, a natural calling. Politics.
But after I finished school, I couldn’t get a placement
All placements wanted someone under 30!
Yea, so it was like, “Oh reject job number 2.”

So I just started looking and looking
And I came across THIS job
As soon as I read the ad, I was like
“This is my job.” I said that.
“Oh this is MY JOB, I’m going to get this job.”

Even though I’m HIV positive I don’t dwell on it.
That’s not why I applied.
This job just CALLED ME.
When I saw that job I was like,
“This is MY job”
It was after the application deadline
So I called
They had just extended the deadline. That day.
So they advised me to apply.
I did and I got this job.
So that’s my current THING.

But going forth, I may have a new calling?
I fancy myself a writer.
I want to pursue a Masters.
I feel that I can talk to someone
And touch them through my own endeavours.
Perhaps I will write a book.
Writing about every day issues.
That have political implication
Since coming to Canada
The meaning of work for me
Has evolved over time
It started being about survival.
When I first came here I was in survival mode
In some ways, I still am, for sure.

But now?
I’m being **called by the heart**.

You know I always hear people say,
“Do what you’re passionate about.”
And I laugh and think,
“That doesn’t pay the rent.”
But when you truly do something
That you don’t believe in
It’s like, “Oh my God I’m going to throw up.”

I want to do something that I BELIEVE IN
Something that I am PASSIONATE ABOUT
I want to pursue MY CALLING
I still don’t know what my calling is, but at least
I am listening for the call …

*It just called me, Norma*

As I listened to Norma’s stories of work — in her homeland and in Canada; within and outside of HIV; in the past, present and future — what stood out was this notion of work as a calling. This calling work evoked translocal cultural narratives of work that were also troubled as Norma located her calling work from her homeland to Canadian contexts. When I initially asked Norma what led her to employment in the HIV sector, she emphasized her desire to pursue
work that was personally fulfilling, socially significant, and utilized her work-related skills and abilities. As our conversations progressed, however, what resonated was that this “call” to work was also emotional and spiritual: she desired work that she was “passionate about”, and “believed in”. Work that “called to her heart”. Yet, Norma did not initially aspire towards work in the HIV sector. She found her AASO employment at a juncture in her life where she was not finding work in her professional fields. Her transition to HIV-related work came after several years of trying to establish herself vocationally in Canada.

When Norma first migrated to Canada, she initially found work in business administration, the same field as her homeland employment. Though the work was less skilled than her previous job, the work supported her stay in Canada, allowing her to complete the immigration process and prepare for her children’s migration. A couple of years after her arrival, however, she became gravely ill and ended up losing her job. Determined to find work to ensure her children’s care, she went back to school, obtained a college diploma, and then a bachelor’s degree. After struggling to find employment post-graduation, she came upon a job advertisement at an AASO. And this job “called” to her.

Although she believed this call to work in the HIV sector was founded in Canada and its cultural values of work, in her sensemaking of this work as HIV caring work, she re-membered the work that called to her back home. Her calls to work evoked varied notions of social responsibility in her homeland and in Canada as well as emotive, emphatic longings to find work that fulfilled personal passions.

**HIV-related work that “just called me.”** Though Norma’s engagement in the social services, including HIV-related employment, fulfil her natural inclination to care for others, she did not specifically pursue AASO employment to perform the social responsibilities of greater
and meaningful engagement espoused in HIV cultural narratives of AASO work. In fact, Norma had not even been engaged in HIV response activities before her work in the HIV sector. Nor was she affiliated with an AASO. Nor, did she receive mutual aid or support from other people living with HIV. In fact, it was her disconnection to Canadian HIV responses that she believed directed her call to HIV-related employment:

And I, even though I’m HIV positive I don’t dwell on it? So I wasn’t using that. That’s why I didn’t know there were agencies. I didn’t even know. Because I told myself that I’m not going to do the whole GROUP THING ONLINE. Because I feel like it will depress me. I tried it and then I was like no it's too negative... So I feel like that’s a good thing because not everyone knows about ASOs, not everyone is keen on ASOs. And so my whole thing is, let’s take THIS THING where it should be, which is everywhere. Not just in the ASOs, in the community. The community already knows. But there are people in universities. Like myself! Who don’t know that there’s a thing like this that exists. — Norma

As a person with limited experience of AASOs and little engagement with other people living with HIV, Norma empathized with other people living with HIV who were similarly not actively engaged. Her first job in the HIV sector became her way to demonstrate how her non-engagement in HIV response activities could also shape service provision. Notably, it allowed her to develop HIV programming for people with limited experiences of HIV-related services in Ontario. Norma believed her non-engagement connected her to people who were less aware of HIV responses, may not want to utilize AASOs or had not developed a sense of belonging with other people living with HIV. Though Norma’s entry into the HIV sector may have differed from others whose histories of HIV-related engagement called them to HIV-related work, Norma’s sensemaking of her AASO employment as an *experiential call* resonated with the other Narrators’ stories of work: being drawn to employment for which they had experiential knowledge and a personal connection.
Although Norma may not have been engaged in HIV responses prior to her employment, her engagement emulated the social responsibilities of HIV-related work for people living with HIV: to “give back” to local AASOs through civic engagement. For Norma, these social responsibilities incorporated the “empathetic” call to work that “helped” other people living with HIV. In giving back through her work, Norma created services that she once desired as a person living with HIV with limited engagement with AASOs.

While Norma attributed this “empathetic” call to Canadian cultural values of work — work as personally fulfilling and socially significant — her call to HIV-related work also re-membered back home, and the passions she once fulfilled through work that cared for her local people and consequently her homeland’s postcolonial liberation.

**Norma’s calls to work back home**

> In my field of work back home.
> I did not choose based on what I was feeling.
> But it was the type of profession that was going to
take me to the top.
>
> So that’s what we strove for back home.
> We strove for good grades
> And
> We strove for a good job.

*Passage from It just called me, Norma*

Norma believed the Canadian cultural call to work differed from back home. In re-membering the cultural values of work in her homeland, Norma emphasized the importance of personal achievements, or “striving”. To strive for good grades. To strive for a good job. To pursue work that took her “to the top”. In comparing the work values of Canada and her homeland, Norma initially emphasized how they differed. Yet in her evocation of homeland work as a call to achieve, I considered what personal achievement may mean for her, and her local
people as an African woman in a postcolonial state, whose homeland experiences shaped how she made sense of vocational striving. Norma noted that the vocational call to achieve was not readily available given her positioning of her local people in her homeland. Decades of European imperialist rule resulted in educative privileges that shaped vocational opportunities:

Because when I went to school, there was one university. And for you to get into that university you had to have a certain last name... And so colonialism really lingers. ... We were taught to be thinkers. And then you have to go to school. And then you have to work for someone. So that's what we strive for. You strive for good grades and you strive for a job. — Norma

Norma emphasized that despite postcolonial independence in her homeland, the colonial artifices continued within education and labour market systems such as who had the opportunity to pursue post-secondary education, and who had access to socially desired jobs. Norma also believed that as a “Black” person, there was a social expectation to strive for educational and vocational opportunities, to advance oneself within a country where colonial histories and its racialized and classed legacies had limited opportunities for peoples of African descent.

These social expectations to strive seemed ingrained in her family’s histories of work. Norma spoke a great deal about her families’ professional achievement despite colonization. These achievements in the face of colonization seemed to underlie social responsibilities to strive in the face of colonial injustices. In our discussions of graduate education and about the prestige of the Ph.D., what resonated for Norma was the political importance of education for people of African descent: in her homeland past, pre- and postcolonial independence, and right now, here in Canada. Norma noted that her appreciation of post-secondary education was not only for its accomplishments but also for its defiance of cultural expectations of peoples of African descent:
Because ... so our parents were born ... obviously not in the city, but they WORKED HARD to get there’s <degree>. And so it was AN ACHIEVEMENT. And so it was sticking it to ... THE MAN. [Yes. Yes.] So it was always instilled in us if you want to be somebody. You have to go to school. — Norma

This notion of “being somebody” instilled by her parents’ educational experiences was not only indicative of her parents’ desires for her to achieve but in the context of colonization, it became a political act to defy societal expectations in a country where colonial relations continued to linger in social stratifications of class, race, ancestral and ethnic lines.

As I thought back to our political debates and listened to the work that passionately resonated in Norma’s story, I started to see colonial defiance and political engagement as a common thread. Particularly, she evoked this colonial defiance in speaking about her homeland activism as a familial calling. As Norma talked about her engagement in political activism, what I began to recognize was the empathetic, experiential, and amorous call to HIV-related work derived from Norma’s familial history of activism. This history was founded in their resistance of, and liberation from colonial oppression:

We have an activist history.
My grandfather.
My father.
And then it looked like it's was going to me.

We grew up during the European Imperialist Regime.
My granddad had moved from his homeland
To the country where I was born
And he had to fight for his LANGUAGE
To be spoken
To be taught.
For us to learn it.
Because during that time
Our language wasn't allowed.
And my father did what his father did. 
He went into the same profession. Teaching. 
Education was a big thing in my country. 
But education was not FOR US. 

During that time, people were restricted from coming into the city. 
And my cousins lived in a rural village. 
If you live in the rural areas, you couldn’t just go into the city. 
Cause they think you’re forming cells 
Groups to fight. 
And so my dad would do underground work to move them. 
And other people. 
Once he got caught. 
They tortured him. Essentially. 

But that didn’t stop him. 
He fought for our liberation. 
We all did. 
We would go to rallies. 
I was just small. 
And it was RISKY. 
But there was a real fight going on. 

And I started to do what my father did. 
Continue the fight for our liberation 
I became a member of an opposing party 
In a one party state 
No one was SAFE! 
We didn’t feel safe. 
It just got dangerous. 
And so. 
We packed up in the dead of night. 
And left. 

So I just grew up with that social justice thing. 
That’s why it hard for me 
When I just see people being treated a certain way. 
To just keep quiet. 
When I first got here 
I was so afraid. 
Now. I feel like I can speak up.
Because
We have an activist history.
My grandfather.
My father.
And now me.

_That Social Justice Thing, Norma_

As Norma spoke about the colonial history of her country, I recognized how her family’s role in the national liberation movements underlays the colonial defiance evoked in her work. During the imperialist regime within her homeland, language and education became sites of colonial struggle. The use of local languages was highly restricted outside of the household; the imperialist language became the primary language of the country and was exclusively used within the formal education system. Hence her grandfather’s fight to keep his indigenous language alive through teaching. Education during the imperialist era was also highly classed. Segregated by race, stratified by region, the “elite” in her homeland, typically people of European descent, had greater access to quality education because of educational segregation. Hence her father’s fight for educational equality.

These political calls for equal rights for their local people — familial legacies of her grandfather and father — continued with Norma. As a member of the opposing party in her homeland, she vocalized her opposition to the current leadership of the African elite. She undertook personal risks to voice the marginalization of her people, which led to her seeking asylum in Canada. What resonated in Norma’s stories of homeland activism was political engagement as a social responsibility, but also political engagement as _a call to her heart_. Her activism connected her to her local people: their freedom struggles of the past, collective resistance in the present, and continued participation in homeland mobilization while living in Canada.
Though Norma did not credit her familial activism to her vocation calls to the heart, her gravitation towards social justice work seemed quite emblematic of a familial call to activism: her grandfather’s desire to pass on his cultural heritage, her father’s fight for equitable access to education, her hope for democracy in her homeland. Their struggle for liberation and human rights. Her familial activism, founded on emotive calls to the heart, was also a cultural call to realize the rights of her people: indignation over colonial oppression, desires for a better life, willingness to risk one’s life for the love of one’s people. Thus, Norma’s cultural calls to work were not born in Canada, but back home: an impassioned call to challenge societal inequities, and an emotive call to care for others vis-à-vis political engagement.

Norma’s calls to her “social justice thing”. What resonated with me in Norma’s calls to HIV-related work were her re-membered calls to back home: her familial history of social activism, and her social justice leanings founded in the post-liberation struggle. Her activism became a stabilizing force as she navigated her senses of belonging in Canada as an African woman living with HIV. Re-membering her “social justice thing” recalled its familial connection which she embodied; moreover such re-membering connected her to her homeland. Moreover, her activism was integral to her identification as a person of African descent and her identities as “African” and “Black”: Norma experiences of colonial oppression as a person of African descent, both her homeland and here in Canada, shaped her political mobilization. She did not leave her social justice thing back home. It came with her. To Canada. Though that might not
have initially been her intention, her social justice thing became actualized in her employment in the HIV sector:

I know that in ASOs you can’t claim anything but ...
I claim it.
I claim this job.
Because I feel that it is my role
To tell people that HIV is not the end of the world.
To make this job mine
I feel I have to break a few rules.
I don’t treat people like numbers.
I don’t treat people as victims
I see my work as some form of activism.
To be a VOICE for VOICELESS PEOPLE
But I don’t feel I can always make these claims
By virtue of HIV responses being led.
By men.
Though I feel that the HIV response is changing
Because of women. Because of US
Claiming.
It's always US who have to change it.
I can’t... We can’t ...
Just SIT HERE and WAIT for them to recognize it!
The challenge is their lack of understanding.
Their reluctance to do things differently.
They won’t see it
Unless WE make them see it!
I’m not a feminist
But.
We need to claim this space.
We need to have our voices heard.
We need to advocate for ourselves.
As women
We need to claim it!

Passage from I Claim it, Norma
Similar to her calls to activism back home, Norma expressed a profound sense of personal and collective ownership to her paid work in HIV responses. While her call to HIV-related employment was founded on a personal connection, I also heard her collective claim to the work. “We need to…” “…for ourselves.” “…because of Us”. In speaking for the collective “we” — women living with HIV — Norma emphasized the collective dimension of her HIV-related work; her call to work was not solely to fulfil personal passions, it was also to assure the collective rights of women living with HIV.

Her lived experience as a woman living with HIV alerted her to organizational issues that discouraged women’s involvement. For instance, she found her AASO had done little to promote itself as a diverse organization, not just catering to gay and bisexual men, so many of the women she served were unaware that general services would be available for them as well. She also felt that the women’s specific services did not address women-related barriers to care, such as access to childcare. As a woman whose lived experience of marginalization shaped her understanding of social inclusion and exclusion and its subtleties within service delivery, Norma believed it was her job to assure that her organization welcomed women living with HIV. Her activist calling implored her to claim agency space for women. Though she resisted this “claim” as a feminist one, she recognized that what she was doing was activist work on behalf of women living with HIV, “being a voice” for people who are often not prioritized in HIV service provision.

Norma’s experiences of colonization and anti-colonial consciousness also gave her insights of HIV-related “politics”. Notably, Norma was cognizant of the exclusion of people living with
HIV who do not fit within the parameters of “priority populations”\textsuperscript{13}, and the segregation of service provision based on population categories:

Norma: Yea. Even with this at work it’s political.

Lori: How so?

Norma: Women they’re always falling through the cracks. Right now the emphasis is on ACB women. But, what about the WHITE women. And ... INDIAN women. And ... CHINESE women? They DO EXIST. Where are they? So.

Lori: It’s interesting hearing a woman WHO IS part of the ACB community talking about other women who are often left through the cracks.

Norma: Yea. I come from a segregated country, I grew up with segregation and it’s (sighs)... it feels like segregation to me. Yea. So it REALLY made me uncomfortable.

Norma recognized how the “segregation” of service provision — or targeting services to priority populations of which ACB communities is such a population — could leave other people marginalized as AASO service users. Although Norma identified as “part of the ACB community”, she also connected with non-ACB women living with HIV. This connection stemmed from a bounded solidarity derived from a common consciousness of exclusion (Portes, 1998). Thus, Norma’s lived experience of “segregation” based on her peripheral social membership in her homeland shaped her solidarity with women who are not deemed “priority populations” in Canadian HIV response activities.

In hearing about the ways Norma strived to claim space for women, I also heard her struggle to do so. She recognized the difficulty of claiming space for women given that the Canadian

\textsuperscript{13} “Priority populations” refer to populations that have been disproportionately impacted by HIV and AIDS in Ontario (Ontario Advisory Committee on HIV/AIDS (OACHA), 2017)
HIV sector continued to be “gay male”-centred. She noted how often she withstood the managerial angst when she advocated for women’s programming. Moreover, she questioned if she had the power to claim space, which I found interesting given her past performances of reclaiming space for her local people in her homeland. Nonetheless, this notion of claim borne from past colonial defiance was present in her AASO employment; she found ways to defy the rules, challenge the organizational status quo, and give voice to concerns that women clients might not articulate to management. She felt empowered to claim space for women living with HIV. Similar to the reclamation she practised in her homeland, these claims were emblematic of solidarity and realizing collective rights. In giving voice, and in claiming space, Norma remembered and rekindled her activist past, central to her approach to caring for other women living with HIV.

Still “listening for the call…” In connecting her AASO employment to political engagement, Norma illuminated the parallels between her homeland activism and her advocacy within her HIV-related work in Canada. Her call to work was grounded in human rights struggle for those who have been marginalized: her local people in her African homeland, and women living with HIV in Ontario. As she spoke of claiming space for people who are marginalized within dominant spaces, I not only heard her HIV survivorship but her survival from colonial and postcolonial struggle.

I also recognized that HIV-related employment was not the work she desired to pursue. Her call to HIV-related employment was also pragmatic. It was about economic survival as she struggled to find work to support her family. As I listened to the multiple calls to work in Canada, what Norma also described were the difficulties translating her skills and education into meaningful work. Her employment in the HIV sector had been her third try to fulfil a vocational
calling in Canada. Moreover, her sensemaking of meaningful work had evolved over her time in Canada as she reunified with her children, gained a different perspective of work, and discovered other ways to unite her activist leanings to paid work.

At the beginning of our conversations, Norma spoke of her AASO employment as “calling to her”. In defining what being “called by the heart” meant to her, Norma spoke about doing work about which she was passionate. Notably, when I asked Norma about the work she would like to pursue in the future, it was work outside of the HIV sector that inflamed her passions:

But going forth, I may have a new calling?

I fancy myself a writer.
I want to pursue a Masters.
I feel that I can talk to someone
And touch them through my own endeavours.
Perhaps I will write a book.
Writing about every day issues
That have political implication.

Passage from *It just called me, Norma*

In our later conversations, both on and off tape, Norma reflected on her desires to pursue a writing career. Since coming to Canada, she had used online forums to continue her activism and hoped to pursue a career where she could communicate homeland political issues. Norma longed for employment that connected to the political movements in her homeland and her familial calls to work; she believed that work in the communications field would allow her to wed her *translocal calls to work*: the amorous, activist, and familial calls engendered by homeland and Canadian values of work. What resonated in her work aspirations was this desire to bring back home forward through “long-distance nationalism” (Glick Schiller & Fouron, 2001): maintaining a claim to her homeland through her continued political engagement on homeland concerns. Her long-distance nationalism as activism continued her family legacy of addressing
social justice issues impacting her homeland communities. It was her hopes to continue her homeland activism, her “social justice thing” that called to Norma’s heart. What also resonated was her pursuit of employment that realized work and personal identities that were not tethered to HIV.

While Norma desired to pursue her writing career, she also struggled with pursuing this employment right now. Taking care of her family was her current priority, and the cost of their care — financial remittances, schooling costs, immigration costs — coupled with the current stability of her employment discouraged her from pursuing her education at the time of our last conversation. And yet, she responded to this amourous call through her continued activist work: writing on blogs, dialoguing on social media, keeping up on current homeland affairs. Though she has yet to pursue political activism as paid employment, her work endeavours continue to heed that call. And she continued to listen to her heart.

The possibilities and challenges of HIV caring work as a “calling”

Since coming to Canada
The meaning of work for me
Has evolved over time
It started being about survival.
When I first came here I was in survival mode
In some ways, I still am, for sure. But now?

I’m being called by the heart.

Passage from It just called me, Norma

In many ways, Norma and my conversations on work came full circle. And perhaps beyond. We began and ended our discussions talking about meaningful work as calls to the heart. We both came to realize that this call to her heart was not just a vocation call to employment that was socially meaningful, it was an fervent call to work that fulfilled her passions. At first, her call to employment evoked a Canadian cultural discourse: seeking work for which one has an affinity
that also has a social purpose. In Norma’s sensemaking of political engagement — as a calling “by the heart” — what resonated was the call to homeland values: striving for social justice and using one’s employment to do so. As Norma contrasted local notions of work in Canada and in her homeland, she illustrated the threads that tied her past, present and future work together, and they were more interconnected than she initially realized.

What resonated in Norma’s story of work were the temporal and spatial dimensions of a vocational calling and the potential of a vocational calling as reciprocated care. For Norma to make sense of work as caring for her, she had to go back home: to re-member the work from which her passions were founded. In re-membering her past homeland activism, she aspired towards politically-oriented work post HIV-related employment. For Norma, re-membering home evoked memories of her political activism; she aspired towards employment that reminded her of the self, collective and social care she had realized in her homeland. In her sensemaking of work as an affective calling, Norma also narrativized ways in which HIV-related employment was meaningful for her such as assuring women-centered services, developing services for people unfamiliar with AASOs, and being a “voice for a voiceless”. While her original understanding of work as a calling spoke to its empathetic call, in re-membering work what resonated was its amorous calling, a call to Norma’s heart.

Although she could re-member activism within her HIV-related employment, such work was an economic call as well. She needed work to assure the care of her family. Given the difficulties that she had in finding fulfilling work in Canada, I could not help but wonder: would HIV-related employment have called to her if she was able to obtain meaningful employment on her first or second try? If it were not for her familial responsibilities, would she have left her AASO employment to pursue a career outside of the HIV sector? Norma’s call to HIV-related work
was as much a call to her heart as a call to survival. She was a single mother who was
transnationally caring for her family, while trying to assure their migration, yet unable to secure
work in the occupations in which she was trained and delayed in pursuing her aspirational
employment. Norma’s employment in the HIV sector came at a time when she needed
employment to care for others: her family. While her current HIV-related employment offered
her some fulfilment, it did not assuage the other vocational calls to her heart. HIV-related work
may have called to Norma at a time in her life, but it was a job for now, not for her future.
“We’re Not Sitting There, Eating Taxpayers’ Money!”: Naomi’s Story of HIV Caring
Work as (Un)Supportive Work

My grandma was the best woman.
I miss her a lot.
She raised me.
To work hard.
Her work ethics was good.
We lived a really nice life.
That’s why. I find it so hard.
Now that I am living this kind of life.

I am living this kind of life
Where I am just
Counting the months.
It’s just
Waiting
Wondering
Counting the days?
Waiting for my ODSP.

AWWW
One month is like one year.
Used to be every 14 days
When I used to get paid.
Now it’s waiting ONE MONTH.
When will this month be over?

I am living this kind of life
Where I don’t have any confidentiality.
Every form, every paper, every request
Everything is being checked!
If I worked. Every cent.
If I request diabetic needles? Every request.
Fill out this paper. Submit this paper. Get your doctor to sign this paper.
To me, they meter you.
I am living this kind of life  
Where I can’t afford to eat healthy.  
I have diabetes!  
I have to, have, healthy food.  
But it COSTS SO MUCH these days.  
You put a protein here, add some fresh vegetables there, perhaps a treat for the kids.  
I ask my daughter, can we be vegetarian?  
Sometimes it’s better to eat junk  
Just buying, without cooking, you know.  
It costs too much!  
TOO MUCH.

I am living this kind of life  
I can’t afford to escape.  
This is a very expensive city.  
How do you survive?  
If you don’t have a monthly bus pass, or tickets.  
You don’t have anything.  
How do you work? How do you live? How do you get paid?  
I don’t blame other people on ODSP or OW.  
If they are sitting in the house, not looking for a job.  
Depression makes you want to sit  
To forget  
To give up.

I want to go to summer school, and take some courses.  
But, I can’t push myself  
I CAN’T AFFORD to push myself  
I DON’T HAVE THE ENERGY to think about it.  
They put you down, down, down.  
For living this kind of life.

Living this Kind of Life, Naomi

As Naomi’s shared her story of HIV-related work she kept on repeating this phrase, “It’s so hard.”. This hardship resonated in “this kind of life” she narrativized as an African woman living with HIV who also lived with disabling chronic pain and diabetes. It’s so hard working in workplaces where her chronic pain was not understood. It’s so hard being on disability supports.
It's so hard for her to find work in Ontario. It's so hard being poor in a “rich” country. It's so hard to live this kind of life. What resonated in Naomi’s story were the labours of HIV, disability and employment that were articulated in her HIV-related work. The labours she detailed were numerous and interconnected. There was the labour of living with the debilitating impacts of HIV and the resulting challenge of finding accommodating, non-stigmatizing employment. There was the labour of being on disability supports when social assistance was devalued. And lastly, there was the labour of being impoverished in Canada, a country narrativized as rich. Naomi taught me about the hardship of HIV-related employment while living on disability supports. Yet these hardships also revolved around social responsibilities — in Canada and in her homeland — to be actively engaged in the labour market. Naomi’s story emphasized the arduous struggle of finding work that cares for her as an African woman living with HIV-related disabilities.

As I explored Naomi’s experiences of HIV-related work what also resonated was this notion of work that was integrally tied to a cultural narrative of Canadian immigration and employment, the narrative of living “a better life” that had cultural meaning both in Canada and her homeland. Naomi also asked me to relay this story of HIV caring work as a hardship because it politically resonated with her. What resonated was HIV caring work as (un)supported work: finding supportive work within the HIV sector and feeling unsupported in her labour market.

14 Throughout this section, I use socioeconomic terminology that references supranational hierarchical classifications based on monetary measures (i.e., “high-income”, “low-income”, “rich” country, “poor” country as per capital Gross National Income (GNI) income groupings or percentage of people living in poverty) (The World Bank Group, 2017) as this terminology best reflects the cultural narratives of “national resources” and “wealth” that Naomi articulated in her sensemaking of her and her families socioeconomic positioning. This terminology also emphasizes how neoliberal ideologies pervades Naomi’s understanding of (un)supportive work. However, I use quotations to trouble these terms as their usage highlights the valuation of countries based on the economic terms, which in turn articulate discursive representations of colonization and capitalism, where “developed” nation many of which are former Imperialist states are presented as “high-income”/“high resource” countries, and “developing” nation many of which are former European colonies are presented as “low-income”/“low-resource country.”
engagement. This story offers another understanding of HIV caring work for African women living with HIV as it emphasizes the importance of income security in caring for them.

The supportiveness of work in AASOs

The supportiveness of (re)finding “community” and reciprocated care through HIV voluntarism: Naomi first introduced me to HIV caring work as supportive work as she talked about volunteerism. Before her diagnosis, Naomi had volunteered within her homeland communities; after her diagnosis, she volunteered primarily within the HIV sector. For Naomi, voluntary work had always been a way of giving back and contributing to the communities to which she belonged. This care work became even more relevant after being diagnosed with HIV. As Naomi described re-establishing her life after her diagnosis, she shared her challenges with social isolation, loneliness, and depression. Though actively involved in voluntarism, she was unsure if she could find acceptance and support in her homeland communities once she disclosed her diagnosis. It was through her voluntary work in the HIV sector that Naomi regained a sense of self, and found social acceptance and support. And her voluntary engagement offered her another community — the HIV community — to which she found a sense of belonging:

When I was diagnosed with HIV? I didn’t know where to go. I was so confused. I was SO ALONE. I was already involved in the community. I was a member of a church I would socialize, go out. They knew who I was. They KNEW ME. But back then I did not want anyone to know I had HIV.
When I started to volunteer
Went to AIDS service organizations
Just pitched in.
They treated me NICE
They treated me VERY WELL.
And I found some REAL friends.
I found a NEW community
An HIV community
Someone who is living with HIV
Someone who is connected to HIV agencies.
MY COMMUNITY.
MY HOME

_Community_, Naomi

Naomi discovered that her voluntary work within the HIV sector allowed her to “feel good”. Through her HIV-related work, she could engage socially with other people living with HIV. In fact, her engagement within the HIV sector gave her a sense of community that she had lost upon her diagnosis. Fear of disclosure and subsequent marginalization and exclusion had encouraged her disengagement from her cultural communities such as people from her church and members of her ethnic communities; yet through her work within the HIV sector, she was able to re-engage in community service with people whom she shared a sense of belonging: other people living with HIV. And this community re-engagement provided her with emotional and instrumental support. For Naomi, volunteering was not only a demonstration of civic engagement within the communities to which she belonged, but it also cared for her. Volunteering offered her the social inclusion that she feared she had lost after her HIV diagnosis. HIV-related engagement as a volunteer was meaningful work for Naomi.

Volunteering also fostered community through civic engagement: giving care back to the communities that cared for Naomi. Volunteering allowed Naomi to contribute to the agencies who provided her with instrumental support upon her diagnosis. Consequently, through her
volunteering, she re-engaged with her homeland as she began to meet other women living with HIV who were from her “ethnic community”. Naomi’s experiences as a woman living with HIV who also shared a cultural affiliation fostered an understanding of their “hurting and hiding” such as HIV-related oppressions, and mental and physical health concerns. Naomi positioning as a worker in an AASO allowed her to provide emotional support to women from her ethnic community, the support she felt unable to access when she was first diagnosed:

Naomi:  I help even my ethnic community, like there are LOTS of women hiding and hurting themselves. So hard you know?  

Lori: I have talked to a lot of women who say that. Do you feel that, do you feel that experience has also pushed you towards volunteering at all? 

Naomi: YES. It will push you! Because, if I can - Even now, even when I am volunteering anywhere else, if I see a woman in there, somewhere, and they disappear. If they are not coming? If I have their phone number, I call them and I say, “Don’t hide! This is for real.” Because it helps me. 

For Naomi, volunteer work became reciprocated care: receiving support from her newly found community of people living with HIV and giving back that care to members of her ethnic community. And in these acts of reciprocated caring, Naomi re-found home: a sense of belonging, solidarity and trust amongst people who understood her experiences of HIV. In giving back through her HIV-related work, Naomi also got back: she received support, friendship, understanding, and social participation. Congruent with the social values of civic participation, Naomi participation was of local value to the AASOs with and for whom she worked; yet this value should also be understood as translocal as it encompassed a social connection amongst people with whom she shared a common history — of HIV, homeland, and ethnocultural identity — and common experiences of living with HIV shaped by ethnocultural and HIV identifications.
Receiving employment supports through one’s HIV-related work: Initially, when I listened to Naomi’s story, I thought that this reciprocated care extended to her paid work. At the time of our first meeting, she had been working in a paid position in the HIV sector for about a year. While attending a volunteer training course, another volunteer, who knew about Naomi’s desires to re-enter the labour market, recommended a part-time, contract food service position at her agency, a job which Naomi had both experience, and a passion. She applied for the job and was hired. Employment in the HIV sector allowed Naomi to do something that she loved and to re-enter the Canadian labour market. And as she talked about this paid work position, she seemed enthusiastic about it:

...I said one day when they asked? I said I loved cooking. That’s the way it happens, you know? Even if it is once a while, I feel LIKE GOOD! Because I feel like I CAN WORK. I can! Most of the time when you are sitting in the house you feel SO BAD [yeah]! But I feel, I cook, I have a job. — Naomi

When she initially described the love of her work in the HIV sector, she did not distinguish between voluntary and paid work. She equated both types of work as active engagement that fostered her sense of belonging and acceptance as an African woman living with HIV. Like her voluntary work, her employment allowed her to get out of the house, socialize, and contribute to local HIV responses. Her workplace also offered instrumental supports desired by employees living with HIV: it acknowledged her health concerns, addressed fears of HIV-related oppressions, and accommodated her chronic pain and limited mobility. Her employer also adopted HIV-stigma reduction policies that embodied GIPA/MEPA principles; people living with HIV were encouraged to work at the agency and received instrumental supports such as flexible work hours and info on work opportunities that facilitated their engagement as employees. Naomi HIV-related work — paid and unpaid — allowed Naomi to contribute to
HIV responses, establish a sense of belonging and reconnect with her ethnic communities in Canada which she found beneficial to her health and well-being as an African woman living with HIV.

**Unsupportive labour of precarious HIV-related employment.** In many ways, Naomi’s employment in the HIV sector seemed like supportive work: she was engaged in work that she enjoyed, recognized her health concerns, and provided some financial remuneration. Naomi’s AASO employment was also supportive of her care needs as a person living with HIV and its episodic and disabling aspects. She also saw the tangible benefits of her work such as the support it provided to immigrant women living with HIV.

Yet her employment in the HIV sector did not provide a living wage\(^1\). Typically, Naomi worked part-time and made approximately $300/month in employment earnings. Because of this limited income, she continued to rely on governmental assistance to supplement her income and disability support needs. Naomi received social assistance from the Ontario Disability Support Program (ODSP Act, 1997), a government program that provided financial support and health benefits to people with a diagnosed disability or illness deemed as impeding full employment (Ministry of Community and Social Services, 2013). At the time of our meeting, ODSP provided financial assistance and supplementary supports to employed recipients if their income did not exceed income eligibility criteria (Ministry of Community and Social Services, 2006b). ODSP also offered extended health benefits (i.e., medication, dental care and vision

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\(^1\) A living wage is defined as the minimum amount a wage earner a household requires based on the cost of living in a community (i.e., food, housing, utilities, transportation, health care, minimal recreation, education or training, and childcare). At the time of this writing, the livable wage in Ontario ranged from $14.15 to $18.52. While the livable age movement takes a rights-based approach to income security it currently does not include calculations of a livable wage for a person living with HIV, or other co-morbid health conditions that expended additional care expenses not covered by public health care (Living Wage Canada, 2013).
care) for people with excessive health care costs if comparable benefits are not offered by one’s employer (Ministry of Community and Social Services, 2006a, 2006b).

Yet in the neoliberal context of work, Naomi’s reliance on disability supports as a person who is employed comes into question. While the Ontario government through its government support policies recognized that some people might be unable to fully engage in the labour market, hence the provision of disability support programs such as ODSP, governmental support programs still apply means-testing that determines one’s eligibility. Despite making an unlivable income in her AASO employment and her requirements for health- and employment-related benefits, Naomi’s eligibility for social assistance has become regularly surveilled since she became employed. It’s this systematic surveillance that Naomi saliently experienced the hardship of receiving social assistance supports.

**Unsupported labour of living on ODSP**

I am living this kind of life
Where I don’t have any confidentiality.
Every form, every paper, every request.
Everything is being checked!
If I worked. Every cent.
If I request diabetic needles? Every request.
Fill out this paper. Submit this paper. Get your doctor to sign this paper.
To me, they meter you.

*Passage from* Living this Kind of Life, Naomi

While ODSP is promoted as a support program that eases transitions into paid work, Naomi’s experience of it countered its “supportiveness”. Notably, Naomi’s employment made ODSP processes more complicated. Because of ODSP’s means-tested requirements, Naomi had to regularly substantiate her eligibility while employed. Naomi was required to meet with her ODSP counsellor every month and submit her pay stubs. Although her income met the threshold for eligibility, Naomi found that since she started working, she had frequently
experienced delays in receiving her ODSP payment which required her to line up at the ODSP office to clarify any issues preventing payment remittance and receive a manual cheque. Sometimes this lineup would be located outside, in public view, which made Naomi fear that someone she knew would see her and figure out that she still was on social assistance despite being employed:

I started my employment four months ago
When you’re not working, they don’t bother you
When you’re WORKING? It feels like you have to DIE!
They have to give stress to you.
I don’t know maybe it is on purpose?

But.
I hear from.
Every. Single. Person.
Every. Single. Person.
On ODSP. With job.
They stress you.
Like it happens to me.

When you work, they bug you. A LOT.
You DROP your paper.
You DROP your pay stub.
And then they say they don’t receive it.
So, they send you letter.
You must come to their office.
And it happens ...
AGAIN and AGAIN.
Even THAT DAY
The day I should see the money (hitting table).
THAT DAY.
But to see the money ...
I have to go line up. On the street.
And it’s EM-BAR-RAS-SING
Lining up on the street.
In public.
But I have to line up.
Because it is Friday.
And I have to pay my rent.

But I have to stand like that, and people are mocking me.

THAT DAY?
I would rather not even,
BE BORN, you know?
That’s what I feel.
Standing THERE.
For an hour and 30 minutes.
On the street.

On the Street, Naomi

Civic engagement in the neoliberal context emphasizes active participation in labour markets: citizens’ rights to social welfare as corresponding with their responsibilities to actively participate in paid work (Fuller et al., 2008). While civic engagement as active citizenship presumes citizens’ rights to social welfare (Crick, 2000), the delivery of government assistance programs like ODSP counters that claim. The systematic processes of ODSP means-testing illustrated the state’s response in neoliberal societies: in the context of minimal government and individual responsibility, the onus was on the citizen to prove that they still required the state’s support to be actively engaged. This requirement to prove Naomi’s need for governmental supports was emblematized through systematic processes; each month, Naomi had to prove her “rights” for social assistance. Yet, these rights became responsibilities, or the labours of social assistance: regularly going to the ODSP office to submit her pay stubs; physically lining up for a
cheque when she did not receive her support income; lining up outside in public view where Naomi felt judged. Paradoxically, while Naomi was striving to be actively engaged in the workforce, she felt punished for being employed because of the systematic processes of social assistance programs. This means-testing continued despite demonstrating need: Naomi’s lived with disabling, and chronic health conditions that met eligibility criteria, and the costs of her antiretroviral medications and supplemental care demonstrated her current income was inefficient to support her health care needs.

Despite being employed, Naomi did not experience her employment as supportive. The precariousness of her employment required her continued reliance on social assistance. The bureaucratic processes of social assistance programs became a constant reminder that her active engagement as a paid worker was not supported by the state. Subsequently, means testing became an assessment of Naomi. And this regular practice of being assessed became another marker of not being employable enough, which Naomi believed was as stigmatizing as living with HIV.

The unsupportive labour of claiming ODSP initially seemed local: or located in “living this kind of life” — the social assistance life — in Ontario specifically, and Canada more generally. Yet, as Naomi revealed the transnational relevance of her income — to support her family back home and demonstrate active participation in the Canadian workforce to her ethnic communities — I recognized that Naomi’s unsupported labour was also constituted within the global neoliberal context of civic participation and its social responsibilities for an immigrant from a “poor” African country who migrates to “rich” Canada.
Unsupported labour of being the “RICH” immigrant worker

I don’t want to sit on ODSP if I have a job opportunity.
I WANT to WORK! I LOVE to work!
Even with the pain
I have pain. Bad, bad, HORRIBLE pain.
But I want to work.
I can WORK HARD. I HAVE WORKED. Four jobs in Canada.
I’m not lazy like people think of us.

We wanted... to BE BIG!
Everybody wants to be - that’s why we came here!
To change our lives.
To run from bad government.
We came here.
For OPPORTUNITY!

Passage from The Opportunity, Naomi

For Naomi, the oppressiveness of social assistance was not only located within the Canadian context, but it was also located back home, anchored in the cultural perceptions and values ascribed to receiving supports from strangers and translocated in homeland memories of work and her ethnocultural social networks. For instance, Naomi’s reliance on governmental supports countered the idealized ”middle-class” life of an African immigrant who was employed in Canadian spaces. Precarious employment and living on social assistance was not the kind of life that Naomi had imagined for herself given the life she left back home was a “really, nice life” with the values of “work[ing] hard” instilled by the grandmother who had raised her. Naomi experiences of precarious underemployment and poverty countered the idealized Canadian narrative of financial independence through one’s employment income. Her experiences also countered homeland assumptions of work in Canada where “working hard” presumed Naomi would live a “really good life”.
Naomi also found that homeland cultural values of financial subsistence shaped how she made sense of social assistance as unsupportive. Particularly, Naomi understood social assistance as “begging”. In describing what begging meant to her, Naomi conveyed the shame ascribed to it in her homeland, a communal culture where support began at home:

Naomi:  (crying) That’s not like how God created us. There is a difference between like people who chose to be on the street and there is a difference [between] people [who] choose to be at home. I know, I don’t blame them that’s their choice. And sometimes the stress you don’t know what to do. Maybe the same thing, ODSP, maybe the same thing makes them to be outside you know? You don’t know what is going on in their mind but … You are included in that. And your community see you and maybe call back home and say, “Oh I saw that your daughter is lining up begging.” You know? (2.3) And for that they judge you, the community judge you.

Lori: How do they judge you.

Naomi: Mmhm. It affects you. A lot. A lot. And. Maybe, it is ok here to beg? But it’s not ok back home to beg you know that’s the difference. [Ok.] It’s not ok even to wear second hand clothes. Yea that’s the way you grow up. Second hand clothes, even when you wear second hand clothes it looks like you are wearing somebody dead. [Ah. Ok.] Yea that’s the way they think. I understand now, but that’s the way they think, yea. I don’t know. I left my country so long ago. I don’t know now, but before it was like that, you know?

In making sense of ODSP as “begging”, Naomi strived to differentiate herself from people whom she believed “chose” to be on social assistance or “on the street”. She even used perceived nationalized differences — perhaps “it is okay here to beg here” in Canada while it’s shameful in her homeland — to differentiate herself from people with whom she lines up at the ODSP office. As she discussed the cultural implications of being seen at the ODSP office and her concerns that community members from her ethnic community would judge her, Naomi conveyed varied local constructions of social assistance, and of its recipients. While the provision
of social assistance in Canada may permit “begging”, it would be impermissible to expect such
government support in her homeland.

Naomi explained that in her homeland, the social responsibilities of support were placed on
one’s family. To beg presumed that one does not have those social networks or supports, which
Naomi explained was another source of shame in her collective culture. Naomi also feared that
if people from her ethnic community who lived in Canada discovered she was on social
assistance, that shame would not only cloak Naomi but her family as well. As Naomi shared her
sensemaking of living on social assistance what she evoked was this notion of begging in her
homeland that she placed in the Canadian context. In this sensemaking, ODSP was not
supportive of Naomi as it positioned her as a person without familial supports. And waiting in that
ODSP lineup, it physically and figuratively positioned Naomi as the person who needed to beg
… on the street.

Yet as I continued to listen to Naomi, was also resonated was that homeland understandings
of support located Naomi as the supporter: the immigrant geographically located in Canadian spaces
was expected to support themselves and families through workforce engagement in a “RICH”
country. As I understood begging from Naomi’s perspective, I thought back to our earlier
conversations, when Naomi talked about coming to Canada for “opportunity”: to “change” her
life, to run from “bad government”, to “BE BIG”! Naomi understanding of Canada as a rich
country evoked cultural narratives of Western wealth and economic opportunity. It assumed that
Naomi as an African immigrant living in a perceived high-income country would become more
financially successful than her homeland-based family. Subsequently, this cultural narrative
presumed that Naomi could financially support her transnational family as well:
It’s just most of the time, I forget myself and live for someone else. You know. And I’ll ALWAYS be there. Though they NEVER thank me? But I say, at the end of the day I don’t have guilt. [Umm hmm]. I do not wait. I said. I don’t want - Like, if something happen, I send, maybe it is 200 dollar I send over there. And I don’t want her, if something happen, and they said, I didn’t help her. — Naomi

Throughout Naomi’s narratives of work, she talked about the financial support she provided to her homeland-based family: paying for the surgery of her aunt, buying fashionable clothing for her cousin, purchasing food for her family the few times she had returned. Consequently, Naomi’s financial responsibilities to her homeland-based family required her to perform this “BIGness” role: the financially successful African immigrant based in a Western country who remits her employment income. For Naomi, remitting what little employment income she earned allow her to maintain this BIGness role as well avoid familial censure.

Yet in performing this narrative of financial BIGness, Naomi subsequently downplayed her own familial support needs:

Lori: Does anyone send money to you?

Naomi: ME?

Lori: Yeah, does anyone -

Naomi: They think I’m RICH y’know?

Lori: Why do they think you’re rich?

Naomi: I don’t know!

I couldn’t help but wonder if assumptions of Naomi’s “richness” as an immigrant living in a high-income country allowed her family to assume that she could financially care for them. Moreover, I questioned if this role prevented Naomi from seeking familial support, even if that support meant reducing their financial dependency on her. I also wondered, if providing
financial support absolved Naomi of the guilt of not becoming the BIG immigrant she had expected to become in Canada.

Although Naomi’s family may have initially relied on her remittances at the time of her departure, they no longer depended on her to subsist. Some of her homeland-based family members pursued graduate education while she could not afford to go to school, lived in houses and on land that they own while she lived in “government housing”, used taxis while she took public transportation. Over the course of time that Naomi had lived in Canada, many of her homeland-based family members gained the financial means to live the kind of life, the “middle-class” life, that Naomi desired in Canada:

Lori: But do they need because one thing, in terms of, are they living comfortably? Or do they need a lot of money from you?

Naomi: No! They don’t need it. She rents a house. Everything. They don’t need it. [Would you say — ] They are okay, but there is always problems. [Would you say that — ] I would not say high class but they are in the middle class.

Lori: So they are middle class?

Naomi: Yes. [ They are middle class — ] They are BIGGER THAN ME. Every single person who complains has their own house. ((hits table)) Really really, nice houses. You understand? [Yes] We have nothing here! [I do understand.] If you go back home? Compared to people even compared to the houses like this? You know [yeah, yeah]. The RICH? That person he says, he call himself poor. But he is not poor. But when you think about it. Big land. Here to buy big land must cost you [an arm and a leg] how hard you — , you would have to be RICH. [Got it. Got it.] Big land and everything is from the land. They get. Vegetables and fruits. Everything. And how come you are poor? Because of your house? No. You are not even poor. Think about this. Every single person if you see it except for the beggars outside? Especially who is living in the rural areas? One day I was thinking I was on the bus I thought I don’t have nothing and these people have this! But they are poor! They call themselves
poor! [ Interesting] No! Here in Canada you have to be ((hits table)) REALLY RICH to get BIG LAND! [ Yes, yeah.]

Lori: Or to get a big house like that [yeah!]

Naomi: You would have to go to like, the city? No. This is the city?

Lori: This is city. The suburbs?

Naomi: Suburbs. [Suburbs] when you go to the suburbs you are like oh someone has, someone has this. And. You have to be rich.[Yes.] We don’t have nothing. Zero. With the government house.

Lori: Wow. Wow!

Naomi: Yeah. And think! Those people are saying “Oh no. I’m poor.”, but they eat even organic food.

While Naomi narrativized her family’s middle-classness, she acknowledged that local and supranational income inequities remained. Naomi recognized that the social welfare state of her country was still not substantial. For instance, paying for surgeries was still a necessity as her country did not have a universal health care system; it continued to rely on user fees, charitable aid, international grants and NGOs along with governmental funding in the delivery of healthcare (World Health Organization (WHO), 2017). Moreover, the financial security her family attained may have indirectly stemmed from Naomi’s financial support; financial remittances can become a familial strategy to increase social mobility and reduce financial risks experienced by family who remain in one’s homeland (Zimmerman et al., 2006). Yet in Naomi’s sensemaking of RICHness what resonated was her poverty while living in a rich country, and her family’s middle-class life while living in a “poor” country. As Naomi grappled with fulfilling her responsibilities to support her family as the perceived RICH immigrant, she questioned if her rights to income opportunities while living in Canada were being fulfilled. She also reflected on
socioeconomic realities of her homeland family and herself: her siblings who remained back home living in houses and eating organic food; she who migrated to Canada, living in subsidized housing and unsure if she can buy meat month-to-month.

Despite Naomi financial needs and limited income, she continued to remit whatever money she made from her AASO employment to her family. As she said, “I forget myself and live for someone else”. That’s the way Naomi grew up. To take care of her family such that they did not need to beg. Naomi economic self-sacrifice for the benefit of her family articulated gendered and nationalized role expectations of African women: to take care of others before themselves and to perform as the RICH immigrant in a Western country.

Reconceptualizing unsupportive precarious HIV-related employment as self-care:

Although Naomi’s story highlighted the unsupportive labour of precarious HIV-related employment, she subsequently redefined her AASO employment such that it was supportive of her. Given the capitalist society within which Naomi lived and the construction of her RICHness as an immigrant living in a Western nation-state, employment allowed Naomi to perform as a neoliberal worker-citizen: where one’s belonging is defined by market production and consumption (Isopahkala-Bouret, Lappalainen, & Lahelma, 2014). Although Naomi did not consider her employment in the HIV sector as a “real job,” she identifies it as such to others:

People, they ask you. People ask you, they ask ((speaking as another person)) “Are you working?” ((speaking as herself)) Yeah, I have hospitality job.” They don’t know how much I make. — Naomi

In talking about her HIV-related work, Naomi highlighted the socially idealized aspects of the employee identity, that she received a wage for instance. While her volunteer worker identity gave her a sense of belonging in HIV community cultures, her employee identity established a sense of belonging in neoliberal capitalist cultures. Naomi uses this employee identity to cloak
devalued aspects of her social identity such as her continued reliance on social assistance while working. In recognizing the social value of the employee identity, Naomi reframed her paid work in the HIV sector — though precariously paid — as idealized employment. In reconstructing her work identity, Naomi articulated a notion of HIV-related employment that was more than just remunerations of pay. Her employment in the HIV sector allowed her to perform as a neoliberal worker-citizen, whose contributions to society derives from labour market engagement.

Once I understood what a “real job” meant to Naomi, an opportunity to perform as an idealized worker-citizen subject, I began to recognize why she always wanted us to meet at Starbucks. Starbucks was not just as a place for us to meet or get coffee. Starbucks offered what Naomi believed was her rights of neoliberal citizenship: to live the middle-class life that was denied to her as a precariously underemployed social assistance recipient. Though Naomi lamented the cost of a drink at Starbucks, she found that by being there alongside others consumers established her belonging in a capitalist society. As a coffee place that signified social affluence, Starbucks allowed her to perform as a person who could afford to buy a drink there. This consumer role countered her positioning as a person on social assistance:

Starbuck’s is better even if it’s $5. [Yes. Yea. Why is it better? Why Starbuck’s over — ] No one knows. If I sit at home, I know my depression can kill me because I was in suicide thinking a lot and when I feel that that’s the way of dealing for me. I know Starbuck’s is expensive. I’m not rich, but I have credit card. Do you understand what I mean? [I do.] — Naomi

Naomi often mentioned Starbucks as a place of meditation and self-care. Throughout our interviews, Naomi spoke of the sense of loss she experienced while at home, stemming from her current health concerns, her challenges with finding employment and other losses in her life. Starbucks became a place that alleviated the stressors and depression Naomi experienced.
because at Starbucks, she could engage with others that did not know what she was going through, allowing her, if only for a moment, to forget she was living with HIV, co-occurring health impairments, precariously unemployment, and poverty. Visiting Starbucks became self-care:

   Every single day when bad health comes and whenever I feel that bad, suicide or something, I said I have to live. I have to push. Then I run to Starbuck’s and sit there. Then I feel better. Then I come home you know. That’s the way I’m dealing. That’s the way I’m medicating myself. — Naomi

As I witnessed Naomi order her drinks, socialize with the baristas, be referred to by name, I noted how happy she seemed in these interactions. I also witness Naomi perform a middle-class life as a Starbucks consumer: a person who could afford a $5 latte in a place where no one would suspect Naomi received social assistance. These neoliberal identity performances — the citizen who contributes to the Canadian economy through economic production and consumption — not only emphasized the fulfilment of neoliberal active citizenship responsibilities as a worker-citizen, it also realized Naomi’s right to live a “civilized life” according to state standards. In neoliberal Canadian society, that civilized life has become a middle-class life and what it represents: financial independence and the available to “freely” participate in economic markets as a producer or consumer.

In these minute acts of middle-classness, Naomi strived to counter social constructions of not being employed enough and to mitigate cultural constructions of begging. Alternatively, Naomi re-membered the universalized ideals of being BIG as an immigrant living in Canada. She temporarily forgot the hardships of finding secure, stable employment as an African immigrant woman living with episodic and chronic aspects of HIV, and momentarily alleviated the stressors and diminished senses of self that can come from poverty and its social denigration.
While active participation in economic markets was a social obligation of neoliberal citizenship, adopting and performing the roles and responsibilities of worker-citizenry fostered Naomi’s senses of homeland and Canadian belonging. In both local contexts, the social role of breadwinner was idealized: employee in the Canadian labour market and financial provider to homeland-based families. In the absence of supports to assuage the stressors of precarious underemployment and impoverishment, performing worker-citizenry became elemental in Naomi’s self-care.

The possibilities and challenges of HIV caring work as employment. For me to understand HIV-related work as caring work for Naomi, I had to make sense of its (un)supportiveness from a local and transnational perspective. Naomi derived many instrumental and emotional support from her HIV-related work: opportunities to contribute to local HIV mandates, access to employment opportunities, and semblances of home and community belonging amongst people living with HIV and her ethnic communities. Naomi’s supportive experiences of HIV-related work highlighted the importance of voluntary engagement and its social contributions particularly for African women newly diagnosed with HIV who are trying to (re)establish their senses of belonging. HIV-related work can offer connections to community and senses of home that can be disrupted due to geographical distance from family, or experiences of HIV-related oppressions and its impacts on senses of self. Naomi’s non-stigmatizing, accommodating work environment supported her health and wellbeing as it provided her with an opportunity to engage in work for which she had a passion.

Yet what resonated was how unsupportive Naomi’s AASO employment had become. Though employed, her income did not provide a living wage. Naomi still required government supports to assure her financial subsistence; yet, she experienced the social censure of being on
income assistance. Notably, she found the means-testing requirements of governmental assistance while precariously employed particularly arduous as she experienced the systematic processes of ODSP’s eligibility testing while employed as censorious of her employment precarity. Yet, all Naomi wanted was the opportunity to be gainfully employed.

As I listened to Naomi’s story of (un)supportive work as an employee in the HIV sector, what particularly resonated was how paid work in the globalized neoliberal context shaped her roles, rights and responsibilities as a citizen in two national contexts. In Naomi’s sensemaking of begging, she recognized the social responsibilities of employment as an African immigrant living in Canada: to become autonomous and financially self-reliant, and to financial care for her family members who remained in her African homeland. As Naomi’s precarious underemployment and health care expenses resulted in her continued reliance on social assistance, Naomi experienced the social sanctions of receiving government supports. Therefore, she devised strategies to demonstrate that she was a responsible: she reconstructed herself as employable enough through economic activities of consumption and paid worker performatives.

Naomi’s (un)supportive work was also emblematic of the transnational scale of Naomi’s responsibilities as a neoliberal worker-citizen, and the role income remittance played in a global economic marketplace. Remittances — foreign goods, currency, services — can foster better economic opportunities for African women and their families; limited economic opportunities in one’s homeland may make migration and subsequent employment a viable alternative to financially support their families (Levitt, DeWind, & Vertovec, 2003). Yet, the cost of this economic exchange was born on Naomi. She bore the financial costs of remitting her limited employment income despite her financial needs. Moreover, it reconstructed her familial relationships, where her employment in a country deemed high-income positioned her as the
“transnational breadwinner”, reframing her familial roles and responsibilities through the neoliberal lens of economic exchange. Moreover, sending money and goods to her family realized gendered responsibilities to care for her family despite geographical distance, and it may have absolved Naomi of the social censure of not caring for her family in other ways. The home care Naomi could not give to a family member post-surgery was mitigated by paying their medical bills; the sporadic visits to her homeland were absolved through paying family expenses when she visited. The surveillance of her social responsibilities became translocated as well: the cultural shame of receiving Canadian social assistance reflected how Naomi’s homeland responsibilities were also censured by the ethnic communities to which she derived emotional and instrumental support while in Canada; this shame was particularly salient because of the communality of her culture along with the cultural expectation in her homeland to care for oneself and one’s family instead of relying on state welfare.

What particularly resonated in Naomi’s stories were the ways in which labour market engagement can be unsupportive of African women living with HIV as people living with an episodic and potentially disabling health condition. What made labour market engagement notably arduous was when HIV-related employment was insecure, and poorly paying. Yet Naomi also illuminated the transnational scale of this unsupportiveness as she was expected to financially care for her homeland family, despite having minimal financial resources to care for herself. The tensions of HIV-related employment that Naomi work story illuminates is the potential responsibilization of African immigrant women as transnational breadwinner-caregivers, who labour in caring for others yet relatively unsupported in their caring work.
“Please Respect Me, Stop Calling Me a Success.”: Nadira’s Story of HIV Caring Work as “Successful” Work

At the ASO where I work
They kept on saying
“You are one of OUR FEW SUCCESS STORIES.”
Oh Yea! Oh yea!
And I had to sit everybody down and say,
“Excuse me?
We need to correct some language here.
I was never a FAILURE.
I was dealing with a lot when you met me.
Living with HIV, living in a new place, as a refugee, with children back home
Social housing, social assistance, school, work, poverty.
I hit ROCK BOTTOM because of my situation.
But it wasn’t a FAILURE.
I was NEVER a failure.”

“I had to deal with a lot of stuff.
A lot of stuff happened AT ONE TIME
And my brain couldn’t handle it.
That’s where I was.
It had NOTHING to do with me FAILING.”

“Failing is ...
I was supposed to do this
But I couldn’t do it
Because of my OWN CHOICES.
These were NOT MY CHOICES
I didn’t choose to be anxious, stressed, overworked, impoverished, depressed!
So, don’t call me a failure.
NEVER call me a FAILURE.”

And they were like,
“No, we don’t mean that you were a failure.
When we say you are a success, we are just saying
That YOU OVERCAME.”
And I looked at them and said,
“Excuse me?
We need to correct some language here.
That is NOT how you say SOMEBODY OVERCAME.
Besides
What was there TO OVERCOME?
MENTAL HEALTH?
It’s dealing. It’s surviving. It’s coping. It’s living.
How do you OVERCOME living?”

“I have worked so hard to build my self-confidence.
To get to this point, I repeat to myself,
‘I can do this. I can do this. I can do this.’
Every time.
‘I can do this! I can do this! I can do this!’
And then you turn around and say
‘Here she is. One of OUR SUCCESS STORIES.’
All the SELF-CONFIDENCE that I built up
Went SH-H-H-O-O down the drain.”

“If you see me as YOUR SUCCESS
You are telling me,
‘You can’t do this. You can’t do this. You can’t do this.’
Yes you are. You are saying,
‘You can’t do this! You can’t do this! You can’t do this!’
Or I couldn’t have done it
Without YOU.”

“You know what?
I am no longer your client.
I am your co-worker.
I am YOUR EQUAL.
I have earned my right to be here.
When you call me YOUR SUCCESS STORY
You are telling me I am not your equal
And you are telling everyone I was YOUR CLIENT.”

“I shouldn’t have to fight for your recognition.
I shouldn’t have to demand your respect
So please, stop calling me YOUR SUCCESS STORY.
It’s NOT for YOU to SAY THAT.”

I’m Not One of Your Success Stories, Nadira
I met Nadira at a time in her life when she was grappling with her positioning as a worker in the HIV sector. She loved her work…but …she wanted to quit her job. Although she found her current position a “fabulous, fabulous job.” and employment in the HIV sector a “great responsibility”, she questioned if she could continue. Even though she had substantial social service work experience within and outside of the HIV sector, she questioned if she was “cut out for it”. While she stayed committed to her work in HIV responses, she “quit every day, every day, every day”:

I don’t know like sometimes I seriously think my kids and my friends always laugh at me and on Monday when they call me and they say, “Where are you?” and I say, “I’m at work,” they’ll be, “O-o-h-h! You went.” (Both laughs) Because I quit every day. (both laugh) I quit every day. (hits hands) Every day I say I’m not going. This is it. I’m done. (snaps fingers) [O-h!] I quit every day/every day/every day, so. — Nadira

She did not always want to leave her employment. In fact, her aspirations to work with people living with HIV changed her employment trajectory. She was drawn to HIV-related work as a service user, which subsequently galvanized her voluntary engagement, and later her employment. She also enjoyed her work as it allowed her to work with African, Caribbean and Black communities impacted by HIV. She also believed that her work contributed to the Ontario HIV ACB Strategy (the ACB strategy).  

As Nadira narrativized her work in the HIV sector, what resonated was both the joy of doing the work and her struggle in doing it. Like other African women living with HIV, Nadira struggled with balancing the “multiple hats” she wore to work as a person living with HIV, a front-line worker, and an advocate for ACB communities. Moreover, she laboured in balancing

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16 The Ontario HIV/AIDS ACB Strategy provides a mandate and plans of action for HIV response activities with, for and by African, Caribbean and Black (ACB) communities in Ontario. (ACCHO, 2013)
her care responsibilities to her employer, her communities, her family, her children, and herself. And while she could still find reasons to continue her employment — the opportunity for full-time work in a preferred employment field, the capacity she built within the work, the relationships she had made with clients, being part of the ACB strategy — she also found other reasons why she should leave. She worked 24/7. She was not taking care of herself. She was burning out. Although the AASO where she worked considered her a GIPA/MEPA “success story”, she felt underappreciated by her executive director, depreciated by her colleagues, overworked and undervalued as a “Black” person, “African” immigrant and person living with HIV. She loved her work. But. She quit every day, every day, every day. What resonated in Nadira’s story were the “successes” and challenges of HIV-related work as “meaningful engagement” for African women living with HIV.

**Meaningful engagement as “having to do this”: Nadira’s voluntarism in HIV responses.** Nadira’s work in HIV responses began in Canada. Though Nadira had been personally impacted by HIV, she had lost friends and family members and had known of her seropositive status for several years, she never felt obligated to participate in HIV responses prior to coming to Canada. Nadira migrated from her homeland to another Western country as an undocumented person. Alone, and without legal immigration status, she was forced to take whatever work she could to take care of herself and her children who remained in her homeland. Until she came to Canada, where she claimed refugee status and began the immigration process, her primary focus was income generation, transnational parenting, and caring for her health.

Nadira’s work trajectory shifted towards the HIV sector upon her arrival to Canada. She became a volunteer at the community organization where she received services, a mainstream AASO in a region that was becoming increasingly ethnoracially diverse. As a client, Nadira
became increasingly aware of the GIPA/MEPA principles and the importance of meaningful engagement of people living with HIV within response activities, including the AASO from which she received services. What resonated in Nadira sensemaking of HIV voluntarism as something she “had to do” were the ways that GIPA/MEPA has evolved into an ideological narrative that promoted the social responsibilities of meaningful engagement for people living with HIV:

Like. I didn’t know much about getting involved. [Ok.] GIPA/MIPA wasn’t a priority to me. [yea] I was so focused in.. Nobody should know. Nobody should know. Nobody should know. So when I came here that’s when it was a different setting, I think maybe because I came here as a refugee maybe it's, everywhere I go was working very closely to these communities? Where outside I didn’t have that.... but here I found there’s m-ore I don’t know, it's a m-ore different setting for me because, it was, when I first came I was introduced to, “Oh you are positive ok. Here is an agency you can work with.” So, the first things that I was met with, “Oh we are looking for VOLUNTEERS? And CAN YOU DO THIS? CAN YOU DO THIS?” So, it’s a more of a, I don’t know what to say (sigh). Like when I really started this was more... I have to do this. [Oh, okay] I have to DO THIS.. So until now, I was getting to know this is a need. We have to be involved in stuff like that. — Nadira

While Nadira may not have been aware of the social responsibilities of HIV response engagement in her homeland, she became increasingly aware of them in Canada. At the time of Nadira’s migration to Canada, the GIPA/MEPA principles were increasingly being operationalized in AASOs to better assure the representation of people living with HIV in voluntary and paid work positions (E. Collins et al., 2007). For instance, her AASO had formalized meaningful engagement of people living with HIV within their organizational policy. She also discovered the extenuating needs for people to volunteer at AASOs. Reduced governmental funding and increased reliance on grant and charitable funding have contributed to leaned out not-for-profit workforces that increasingly relied on voluntary work to address service needs (Van Gramberg & Bassett, 2005). Through Nadira’s involvement as a service user,
she became conscious of the interconnection between greater involvement and meaningful engagement of people living with HIV, and the human resource needs of regional AASOs: they required a voluntary workforce and people living with HIV to meet organizational mandates of service provision and meaningful engagement. In Nadira’s story, the solicitation of people living with HIV to volunteer based on what they COULD DO also promoted HIV-related work as something they HAD to do. GIPA/MEPA principles became a rallying cry for her engagement: as a person living with HIV, she had to be involved in the response.

Nadira also recognized other interconnecting reasons to be involved in HIV responses as an African woman living with HIV. For instance, her experiences as a “Black” person and “African” immigrant alerted her to the lack of culturally responsive services for African, Caribbean and Black people impacted by HIV in her region. As she interacted and connected with peoples of African descent, she understood meaningful engagement in HIV responses as something she wanted to do on behalf of ACB communities. Initially, Nadira questioned the notion of volunteering as altruism, but found connections with other people with whom she identified, notably people living with HIV who identify as African or Black:

I remember when someone told me you have to volunteer [for this organization] For free? (I laughs) No I looked into what’s in it for me, and all that kind of stuff then I noticed. I remember my first group that I attended, a support group that I attended, it wasn’t... a pleasant meeting, but I saw something in it because I connected with somebody that, I connected with SOME ladies from the group that I’m still friends with, and now are my family members [oh wow!] from that first group. So volunteer work. It was FUN, I enjoyed every bit of it. — Nadira

As an African woman living alone in Canada, the friendships Nadira made with other African immigrants became integral to her emotional and instrumental support. She also found that her volunteer work allowed her to work in close collaboration with communities of African
descent in her region. These senses of belonging — finding “family” in the support groups she attended, meeting other people with whom she shared a racial, ethnic, and regional identity, and feeling connected to HIV responses as an African woman living with HIV — shaped her experience of meaningful engagement. While she desired to volunteer, she also recognized her compulsion to volunteer: as an African woman, a Black woman, an immigrant woman and a woman living with HIV. Her compulsion to do this may have originated from the HIV cultural rallying cry of greater engagement, but it also became her own rallying cry to DO THIS. And so she did. She heeded the call to volunteer in HIV responses in her region. To join advisory boards. To offer support service. To do outreach. To educate. To care. She heeded the call to greater involvement in Canadian HIV responses as a person living with HIV; it was also meaningful engagement with the African and Black communities with whom she identified.

Nadira decided to volunteer at the AASO from which she received services. Her only stipulation? Keep her status confidential:

The agency itself, the staff knew me as a client but everybody else, even at the volunteers knew me as a volunteer. Maybe, I don’t know, maybe they knew, maybe they didn’t know I don’t know but ... I said I don’t want anybody to know? I’m just involved because of ... the HIV which is endemic in ACB communities. That’s why I’m involved because I’m a former African and I’m Black. ... So I never, and I asked people, I asked my support worker and I asked everybody that I volunteered with and I said, “Listen, when we are here I’m just a volunteer and I’m comfortable that way. And I hope you support me.” ... Right? Because I want to do this but I don’t ... Everybody knows everybody. [Yes]. Everybody knows everybody. And I’m coming from <Homeland>. Where. I’ve had. People around me pass away from HIV. And I’ve seen the STIGMA surrounding THAT and I didn’t want none of that. I didn’t want none of that. I wanted people to treat me like ME. Little did I know HIV’s part of me too. (laughs) — Nadira

Though Nadira had selectively disclosed her status, she did not want to “come out” through her work in an AASO. As Nadira explained to me, her concerns derived both from her
experiences of HIV in her homeland, and the realities of living in a region that is not ethnoracially diverse. She had lived in a country where HIV had been endemic and had lost loved ones to AIDS. She was also aware of the discrimination directed towards people living with HIV. Moreover, where she currently lived her ethnoracial community was small: “everybody knows everybody”. In this small ethnoracial collective, Nadira found a communal interconnectedness that buffered being away from her homeland and adjusting to Canadian life. And yet, the small size and communality of her ethnoracial community made disclosure concerns more salient. If more people in her community knew about her status, it would be difficult for her to control the narrative of her seropositivity, including with whom she shared her status. Although Nadira realized that “HIV’s part of me too.”, her initial desire to keep her status confidential while continuing to volunteer may have also derived from her desire to control the narrative of how she defined living with HIV and her identity as a person living with HIV. Keeping her status confidential within her work reassured Nadira that HIV did not determine how other people saw her.

Nadira’s original impetus to engage in HIV responses may have arisen from the HIV cultural narrative of meaningful engagement as active engagement for people living with HIV; yet, Nadira’s belonging as an African, an immigrant, and person of African descent also underlay her senses of responsibility to care for her communities. For Nadira, other personal and collective memories and senses of responsibilities — as an African immigrant, and as a Black person — induced her involvement in HIV responses. Volunteering became work that fulfilled social responsibilities to Ontario’s HIV strategy and social contributions to communities to which Nadira belonged as an African woman living with HIV.
Meaningful engagement as a “chance” at employment. Nadira’s voluntary work in HIV responses also inspired her pursuit of HIV-related employment. Though she had initially desired work within the general health care field, Nadira’s volunteering experience inspired her to work in social services, with a focus on HIV service provision. After receiving her diploma, an opening came up at the AASO where she received services. She applied and got the job.

I remember talking in one of my volunteer [yes] positions, and I said, “So what does someone that does this work have?” And I said I can do this. So I went back to school. I remember the former strategy worker used to say to me, “I don’t trust you, Nadira, you going to take my job? And I didn’t take her job she retired. [Ahh] Not retired but she, she resigned, which was, she left. So. And I got a chance. And I’m grateful for that. — Nadira

As I listened to Nadira speak about the “chance” she received to work at her AASO, and how she was “grateful”, it embodied a tension in me. I couldn’t help but wonder: how did voluntary work that Nadira “had to do”, become paid work for which she was “grateful”? It pointed to the political economy of gratitude where a person living with HIV may feel thankful for their HIV-related employment yet the opportunistic exchange for both parties and its power relations is not amply recognized (Greene, 2013). While Nadira was grateful for her employment in a preferred field, her AASO benefited from hiring a trained social service employee with experience in HIV. Furthermore, this gratitude came from a person who was a former client at the AASO who hired her. In this milieu, HIV-related employment can be perceived as an intervention, where promoting such employment as agential empowerment and capacity building becomes an extension of HIV service provision. HIV-related employment as intervention operates within service user-service provider power relations: gratitude is bestowed to the AASO for meaningfully engaging a person living with HIV.
Nadira’s gratitude also articulated supranational power relations: the racialized immigrant woman living with HIV bestowing gratitude to the mainstream Canadian organization that hires her. Such gratitude narratives are commonly associated with Global South-Global North migration experiences: Global South immigrants are expected to be grateful for the opportunities provided in their Global North host countries (Nayeri, 2017). Yet this patronizing notion of gratitude magnifies colonial power relations which, consequently, promotes the superiority of Global North host countries and demeans the social contributions of Global South countries and its peoples. As such, Nadira sensemaking of Canadian HIV-related employment as a “chance” for which she was “grateful” was constituted within the context of HIV service provision and its power relations which in turn intersected the social relations of global migration, supranational hierarchies, colonial histories and geographies of power. In Nadira’s understanding of her employment as an opportunity for which should be grateful, she did not fully recognize it as a job that she deserved.

While Nadira expressed appreciation alluded to HIV-related employment as beneficial, her desires to “quit every day, every day” suggested that her employment came at some costs. For instance, with the opportunities for employment came reduced access to HIV-related services. Since becoming an employee, Nadira could no longer avail herself of the services that she previously received at her agency. As Nadira narrativized her transition from volunteer to employee, she also revealed the tenuousness of her confidentiality that previously wasn't a concern when she was a volunteer. She also suggested that the nature of her work and its workload stressed her out. So, at what cost could this chance at HIV-related employment have been for Nadira? Employment in an AASO where she was once a client seemed to come at some costs to her own self-care.
Meaningful engagement as a “success story”.

At the ASO where I work
They kept on saying
“You are one of OUR FEW SUCCESS STORIES.”
Oh Yea! Oh yea!

Passage from I’m not one of your success stories, Nadira

Nadira’s transition from voluntary engagement to employment also raised questions about how the former service user who is HIV, African, Black and female is positioned as a “success story” of meaningful engagement at her AASO. When Nadira spoke about her transition from the voluntary work that she thought she should do as a Black, African immigrant woman impacted by HIV, to the employment that she thought she could do as a social service worker with experience in HIV responses, what I noted was how the shift from volunteer to employee also shifted how she was positioned as a “peer” in her AASO. She continued to see herself as a peer to agency clients, but she also considered herself a peer to her colleagues. Other people positioned her differently. Her paid worker role positioned her as a professional within her agency. Since she was hired in a non-peer role, many clients were unaware of her status. Yet she also spoke about how she was differentially treated as an employee, which she attributed to being a former client at the agency where she worked. Other staff members referred her as their client “success story” which she believed had become the discursive lens in which her employment was regarded: a successful transition from service user to service provider, voluntary to paid work, poverty to financial security.

At the time of our interview, Nadira was one of few staff members whose seropositive status was known to staff. She was also a staff member who was a former service user. Nadira’s AASO employer would publicly repeat Nadira’s story as a success for the organization: the former service user who was now a service provider, and a former volunteer who was now an employee,
In some ways, Nadira’s experience did echo the **dominant narrative of GIPA/MEPA as meaningful engagement**. Her voluntary involvement in her AASO inspired her to pursue social service work in HIV-related service. Once she graduated from school and got full-time employment, she became financially secure which allowed her to leave social housing, transition of governmental assistance, and sponsor her children’s migration to Canada. I could understand why Nadira’s experience could be understood as “successful”.

However, I also understood why Nadira resisted this story-tell. This success story constructed her successes as *overcoming* personal adversity without acknowledging the personal and social conditions within which she pursued her career: returning to school as a mature student, working part-time while going to school, living on limited income, adjusting to life in Canada, and transnationally caring for her children. Furthermore, Nadira was selectively open about her status. In discussing her successes with people outside of the agency, her work colleagues were inadvertently disclosing her status and discounting her expressed desires for confidentiality.

In the agency’s telling of Nadira’s story as one of *their* success stories was another story: that Nadira’s successes were not about Nadira at all. It was about the agency. Nadira story became a story of the **successful operationalization of GIPA/MEPA within the AASO** and their role in Nadira’s achievements. In this narrative, Nadira’s “successes” articulated the agency’s benevolence towards people living with HIV. This benevolence was oppressive. It attributed the challenges Nadira faced to her, and not to the social and structural conditions in which she was working. It attributed Nadira’s successes to her agency, not to her own initiatives. In constructing Nadira’s achievement as organizational successes, and her challenges as personal ones she overcame,
Nadira was positioned as the service user in need of care from the benevolent Canadian social service agency.

Her positioning as a former service user who was now an employee also shaped Nadira’s sensemaking of her peer-ship with her work colleagues. Throughout the interview, she remarked that the primary challenge she experienced was getting their respect. They questioned her judgement. They vetted her client recommendations with their executive director. They did not listen to her opinions. These continuous experiences of being invisible as a front-line worker made Nadira more aware of her visibility as a former service user. In this visibility, however, they did not see the “success story”; instead they saw Nadira at her “worst”:

And I’ve had conversations. But nobody listens when I talk at my office. And I say, “You don’t understand. RIGHT NOW all of you have seen me at my worst. Right? At my worst. I haven’t seen you at your worst so you have the upper hand. I don’t. So every time I’m with you, a piece of me always falls apart. A piece of me.” So I always tell them to say, “You know I know we’re equals. I know we’re everything. But. There is that piece of me. That you’ve seen me cry. That I’ve come to you for that little help.” Like it is very very very challenging. — Nadira

Nadira believed that her co-workers’ devaluation of her as a work colleague illustrated a continuing service user-service provider power dynamic, and that their questioning of Nadira’s work as a service provider seemed indicative of their perception of her as a service user. Not Nadira the volunteer. Not Nadira the advisory board member. Not Nadira the social service worker. Not Nadira their work colleague.

Nadira’s devaluation also intersected with her social positioning as a person living with HIV who was an immigrant and person of African descent. As Nadira narrativized the devalued experiences of clients who shared similar social locations, she also highlighted the professional devaluation she experienced within her agency. For instance, in relaying how other staff
members viewed another “Black” employee at her organization, she emphasized how they stereotyped people of African descent as impoverished:

Because before they never used to have a Black person. They HAD a Black person, I can’t say they never used to have a Black person. They HAD a Black person. But... they never really considered her as Black because she was very light. You know? [Yes] With long hair. [Yes] You know what I mean? And I’m very Black with kinky hair. [yes] So there’s a difference there. Right? [Yea] And they’ve said like she never used to even be Black, she didn’t grow up in poverty or anything. — Nadira

She also reflected upon the oppressive stereotypes of people living with HIV that were upheld at her agency — existing on the social margins, and dying with HIV — which ran counter to lived experiences of many African immigrants who were accessing services at their organization:

EVERYBODY is going back to school. EVERYBODY is graduating. People ARE DOING, people ARE WORKING as PSWs. It’s JUST AM-AZ-ING the amount of intelligent people on our client load. It’s, the only thing is. I think as an organization we need to remove ourselves from that mentality. I think despite what they say, they still have that PHAs are at the bottom like they are [I’ve heard that –] you know like ABOUT TO DIE. — Nadira

While many of Nadira’s clients were achieving personal successes — going back and graduating from school, gaining employment — that emulated Nadira’s own life, her work organization continued to uphold this deficit ideology of people living with HIV, African immigrants and Black people where their marginalization was inherent to their social grouping rather than to sociopolitical relations (Gorski, 2011). In re-membering these specific examples of marginalization, Nadira also made sense of her colleagues’ devaluation of her. Paradoxically, in positioning Nadira as one of their few success stories, when filtered through this deficit

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17 PHA is an acronym for people living with HIV.
ideological lens of people living with HIV, African immigrants and people of African descent, Nadira’s work colleagues positioned her as the worker perpetually at her worst. Her worst immortalized in the stereotypes of people living with HIV “at the bottom”, Black people “living in poverty”, and African immigrants living with HIV as incapable of finding employment. Moreover, in constructing Nadira as a success story, her co-workers were distinguishing her as not their collegial peer, and consequently, not their equal.

**“OUR” successes: Nadira re-defining HIV-related work as “successful work”**

For Nadira to make sense of HIV-related work as “successful work”, she had to re-find what made such work meaningful for her: working alongside the communities to which she belonged. Moreover, she also had to consider the importance of her work to the communities to which she identified. Notably, she recognized the importance of her HIV-related work in disrupting oppressive stereotypes of African immigrants and women of African descent. It was in redefining success that Nadira found self-care.

*Meaningful engagement as kinship work as successful work:* Nadira resisted these labels of “success” being affixed to her as an African woman living with HIV who was employed in the HIV sector. Moreover, despite the marginalization she experienced from her professional colleagues, she established peer-hood through her work. In her reconceptualization of success what resonated was that “success” for her was not a solo effort. Her sensemaking of success drew from what initially made her work meaningful: working alongside communities to which she belongs. To resist the oppressive ideologies that operated within her agency, Nadira invested substantial time working with African, Caribbean and Black communities in her region. Before her employment, her organization was not even aware of the ACB Strategy. During her employment tenure, she worked with ACB communities in her area to assure that the strategic
directions of the ACB strategy were implemented at her agency despite the limited financial resources directed to its implementation. Nadira considered the programming that she had developed alongside other African, Caribbean and Black peoples as testimonials of “OUR” successes — the success of working collectively with African, Caribbean and Black peoples impacted by HIV:

I have a woman’s group that I’m very proud of, that I started and I started with oh one of the PHAs. She’s the lead. Like I’m just there to request money, (laughs) to request money, and maybe book a venue or something like that. But. She’s the one that’s responsible to inviting people. She’s the one, like we can talk about. So for the cooking segment, what are we going to do today? She’s the one that said, “You know what? The last time when we were talking, people would say this,” and we made sure that is available. We always, our women’s group is always successful. Always always, to a point now we have to look for funding. (both laugh) — Nadira

Perhaps because of the oppressive models of service provision witnessed at her agency, Nadira engaged in anti-oppressive approaches that subverted oppressive ideologies of African immigrants, peoples of African descent and people living with HIV. She actively engaged people living with HIV in program planning that she delivered, integrating culturally responsive approaches to programming for ACB communities, taking African, Caribbean and Black service users to retreats outside of her region, and working weekends and after hours to assure the continued successes of ACB programming. This active engagement not only allowed Nadira to meaningfully engage African, Caribbean and Black peoples on their own terms — developing programs that had tangible benefits for them and fostered their capacity within HIV responses — it also resisted the deficit ideology that her agency had operationalized within service programming.

In working alongside people to which she had a communal belonging, Nadira established a peer-hood that fostered her own successes within and outside of her employment. She spoke of
the co-learning that happened in her work, where she’s “took in” stories from service users while at the same time provided them with support. She considered this “education” as supportive of her successes in life: how she approached her work, made personal decisions, and raised her children:

Nadira: Like I’m one person that learned from other people. [yea] That’s one thing about me. I sit with the clients and I’m listening what’s happening, I’m listening, I’m/taking/in I’m/taking in, I’m/taking/in I’m/taking/in. And … I support them the way they need to be supported, but what they don’t know is they HAVE educated me, they HAVE given me SOMETHING that anybody else couldn’t give me.

Lori: Have you ever told them that?

Nadira: Yea I do. And I said, “You have to understand this is a two-way traffic. You help me. I help you.” That’s how… You know so I help you, you intend, you don’t know about it but YOU GUYS have helped me a WHOLE LOT. And most of the successes I have had … with that in making decisions in my personal life? Or in relationships? Or with other people? I have learned from listening to your stories.

Notably, she found capacity building as a “two-way traffic” where knowledge sharing was reciprocated between her and her clients. These client interactions appeared to me as reciprocated care — supporting each other in navigating everyday life — that resisted the professional-peer boundaries and its power relations. Furthermore, these dialogic exchanges seemed to help Nadira make sense of successful work that defied deficit ideologies of “overcoming” adversity. For Nadira, success derived from learning from other people living with HIV, particularly people with whom she identifies, Black people and African immigrant peoples. For Nadira, caring for each other as Black, African and people impacted by HIV is “two-way traffic”; within this reciprocated care, Nadira has found the peer-hood and support that she had limitedly received from her professional colleagues.
“It’s a house full of successes”: Translocally conscious mother work as successful work. Nadira also conceptualized “our successes” in relation to her mother-work. While she conceptualized mother-work as familial successes, she also illustrated mother-work as community responsibilities to counter the deficit ideology of racialized oppression and assure the upward mobility of their children. When I asked Nadira what she envisioned as her future employment, she initially spoke about quitting her job within the next year. Then she talked about going back to school to pursue another post-secondary degree. At the end, she spoke about her aspirations for her children. Nadira’s sensemaking of her successes also drew from her family: the ability to re-establish her family post-reunification, and her children academic achievement post-migration:

When you asked me where I see myself in five years
I didn’t talk about me.
It’s because my life revolves around my children.
For me, family comes first.
And my children, I want them to do better than me
Even if it means that my job will suffer
Because I know their successes are my successes, right?
So where I see myself in the future
Is mainly going to depend on my children,
I think.
As much as I love what I do
I think my children come first.
Yea.
My children come first.

*My children come first, Nadira*

Because of the prolonged duration of Nadira immigration processes — arriving in one country as an undocumented person, then coming to Canada to seek asylum — it delayed reunification with her children. Nadira’s children arrived in Canada during their adolescence. They navigated Canadian immigration systems while adjusting to its educational systems, and
adapted to living in Canada while at the same time relearning their relationship with Nadira after several years of living apart. In speaking about her children, Nadira reflected on what they had been able to achieve during their short stay in Canada: graduating from high school and acceptance in professional programs at their respective universities. For Nadira, her children’s successes were a testament that they had “successfully” navigated Canadian social systems post-migration, and able to advance socially in Canada through professional education.

These notions of success initially seemed to echo social responsibilities of newcomers to integrate to Canadian society: adaptation to social systems and adopting cultural practices to better assure they become “productive members” of Canadian society (P. S. Li, 2003). Nonetheless, what also resonated in Nadira’s story were the social responsibilities Nadira recognized — as a “Black woman” and as an” African immigrant” — to assure her children’s successes. Notably, her children’s educational successes were counter-narrative strategies that resisted the deficit ideologies of African immigrants and women of African descent. In her sensemaking of her children achievements, she spoke to the necessity of it in Canadian spaces, given the oppressive ideology of newcomers, and Black women being dependent on the social assistance systems and prone to poverty. So, in reflecting on her experiences of when she first arrived in Canada, Nadira also illustrated why for her, her children’s successes had to come first.

I don’t want any of my daughters to become a statistic
Another BLACK WOMAN on social assistance.
No.
I’m going to push them to get an education.
There are enough of us that are struggling, right?

My daughters are Black women ...
If they don’t have an education, then what?
Then...what?
I’m not saying that Ontario Works is not a good program  
It has helped a lot of people that are in need.  
But I know how BLACK WOMEN on social assistance are portrayed.  
How NEWCOMERS are portrayed.  
ANOTHER Black woman on social assistance  
ANOTHER newcomer struggling  
ANOTHER statistic  
And, It’s not a good place  

Passage from, *It’s not a good place*, Nadira

Nadira’s mother-work in assuring her children’s successes did illuminate the gendered responsibilities of caring: to assure the vocational “successes” of one’s children as paramount to mother-work. Yet, in reflecting back to her own experiences — as a “newcomer” and as a “Black” woman, juxtaposed alongside deficit ideology narratives of African immigrants and people of African descent she encountered at her agency, Nadira emphasized the intersecting responsibilities of “Black” and “newcomer” motherhood. As a woman living in a country that portrays immigrants and women of African descent as deficient and in need of rescue, her children’s educational achievements and subsequent employment in their professional fields of study could counter the deficit ideology that had been applied to Nadira — as a recipient of social services, as a client — from which she wanted to shield her children. Although Nadira framed the success of her children as reciprocated care, her children’s successes were her successes, she also acknowledged that she was willing to “suffer” vocationally to ensure her children’s employment aspirations. This suffering included remaining in her current employment despite its stressors and a delayed return to school though it could have aided her transition out of her current job. Nadira saw *these vocational choices as necessary for the successes of her family*: her mother-work was paramount to her sensemaking of HIV caring work as successful work. Assuring her children’s successes went beyond mother-work responsibilities; they became a
social responsibility that many immigrants parents of African descent are required take on to
assist their children in combatting systematic racism that becomes embedded in the community
responsibilities of Black/African uplift of successive generations (McLane-Davison, 2015).

Reflecting back to the start of our conversations, where Nadira grappled with working in the
HIV sector and pondered leaving, I began to fully realize why she remained. Her families’
successes derived from her successful work in the HIV sector: her employment allowed her to
reunify with her children and establish income security and stability for her family. Her successes
as a worker in HIV responses became foundational to her family successes as well. Moreover,
combatting systemic racism underlay her mother-work as an African woman, immigrant and
person of African descent. So, I wondered if Nadira would quit her job if it offered the financial
security necessary to support her children’s professional aspirations. I wondered if she would go
back to school if her children’s education required her full-time income. Though she quit her
AASO employment, every day, every day, every day, I wondered if she would. Or could. For her
employment, and the income it provided, was meaningful to her children’s successes. That might
not be the notion of success articulated within the GIPA/MEPA “success story”, yet her
children’s accomplishments were the success stories that mattered the most to Nadira.

The possibility and politics of HIV caring work as “successful work”. What Nadira
illuminated in sharing her stories of work were these varied narratives of HIV-related
employment as success testimonials. Her stories reflected upon the many ways her engagement
within HIV responses had been meaningful for her, such as enabling her to pursue employment
in the social service field, kindling her desires to further her education, and providing a
vocational avenue to work with the various communities to which she belongs. She also shared
how her engagement had been repurposed as an organizational “success story”, a testament of
GIPA/MEPA in operation at her workplace. Consequently, her stories of successful work articulated racialized, gendered, nationalized perceptions of success for African woman living with HIV.

Nadira’s story raises questions about the moral implications of hiring a former client as an employee and its inherent power relations. Nadira story suggests that the service user-service provider relationship can become enmeshed within the employer-employee relationship; particularly, the service user performative can become the role employees living with HIV embody in the workplace. Consequently, the capacities that they bring to the work may not be fully recognized. Particular to African women living with HIV, employer-employee relations are intermeshed within power relations of race, nation, gender and HIV-status. Saara Greene (2013) suggested that an ethics of reciprocity should consider the moral implications of hiring African women living with HIV in AASOs such as how power relations are negotiated and the systemic issues that frame employment relationships. Role transitions of employees living with HIV require careful consideration of their former role as a client and how it interfaces with their positioning in the workplace and their relationships with non-HIV positive colleagues. Moreover, a reciprocal ethical relationship between employer-employee would also recognize that along with the benefits of working in an AASO; such work can come at some cost to the employee such as lost service access at one’s AASO or lost anonymity as a person living with HIV. Listening to Nadira, I recognized that AASOs should critically reflect on the implications of HIV-related employment for their employees living with HIV, and how the benefits and costs may differ for each individual, and shift over the course of the working relationship.

Nadira’s story also illuminated how the meaningful engagement of people living with HIV can become HIV ideological success stories that promote the employment of people living with
HIV in AASOs. Yet, there exists the tension of personal stories being appropriated for institutional benefit. For instance, HIV-related employment as a success story could differentially position employees living with HIV which in turn tokenizes their involvement. In Nadira’s case, I questioned if the success story narrative fostered this perception amongst her work colleagues that her seropositive status was her primary qualification despite her work experiences, employment background, education, and experiential knowledge of the HIV sector. Nadira story highlights the multiple skills and experience African women living with HIV often bring to the workplace that can be subsumed when their seropositive status is the sole attribute on which work colleagues focus.

Furthermore, the operationalization of the GIPA/MEPA narrative within HIV-related employment policies and practices could potentially overlook the potential costs of success story-telling. For instance, will employees living with HIV be able to control the narrative of their work trajectories, or will their work stories become the property of the agencies that employ them? Will telling the stories of clients who become workers differentially position them in the workplace? For Nadira, her organization’s success story-telling not only publicized her status without her consent, it differentially positioned her amongst her colleagues who status was HIV-negative or unknown within the workplace. This differential positioning as a former client living with HIV made Nadira feel like she was not perceived as an equal amongst her work colleague despite the varied experiences she brought to the work.

Additionally, success story-telling can promote an exceptionality discourse of African women living with HIV that articulates intersecting gender, race, ethnicity, nation, and HIV geographies of power among others. For Nadira, she recognized how this notion of her “overcoming” as an African women living with HIV was framed by stereotypes of people living
with HIV (existing on the social margins), immigrants (unsuccessful vocationally), and women of African descent (living in poverty). As such her AASO success story-telling of her “overcoming” promoted deficit ideologies that articulated intersecting gendered, racialized, and ableist stereotypes of African women living with HIV.

As Nadira questioned if the “success story” narrative espoused by her AASO was truly her own, she also reconceptualized what success could mean for her as an African woman living with HIV. What resonated was the communality and translocality of successful work for her. She attributed her successes to meaningful engagement with the communities to which she belonged: working alongside African communities and Black communities to mobilize around HIV responses in her region and actively engaging peoples of African descent who are living with HIV in program planning and delivery. Nadira also found success through the achievements of her children; assuring that their successes countered the deficit ideological narratives applied to her in Canadian spaces. Her translocal work — social networks and collective advocacy with peoples of African descent, a continuation of her mother-work during migration and reunification processes — were seminal to her sensemaking of successful work.

Nadira taught me to reconsider the dominant narrative of HIV caring work as successful work, especially how the caring work of people living with HIV in AASOs can become re-narrativized as organizational success stories. Nadira’s story of HIV caring work as successful work can help us understand the politics of HIV caring work as success story-telling if it does not realize the rights of African women living with HIV to define successful work on their own terms.
“It’s Not Easy...But, It’s Worth It”: Miriam’s Story of HIV Caring Work as Emotional Work

Working in the HIV field is not *that easy*
As a person living in this situation you experience *some challenges*.
I’m tasked with calling the *women* for our group
I call every lady to inform them of the meeting as a reminder.
And most cases when *I call*, they start telling me
Their issues.
I say, “Hello, how are you?”
They say, “Well, you know,
This is what has been going on.”
“I have issues with *my medication*.”
“I have issues with *my children*.”
“I have issues with *my boyfriend*.”
“I have issues with *my husband*.”
So it’s an ongoing *drama*.
But not an *intended one*.
It’s something that they cannot *avoid*.
It’s part of *life*.
And it is not just HIV related, you know.
It’s everyday issues that everyone has.
*Everywhere*.
But there is also HIV.

Working in the HIV field?
No, it’s not easy...
But, it’s worth it.
I was talking with my supervisor. And I brought up this issue to her. And she was like, “How come they don’t talk to me?” But that’s how it is. I deal with them. With each of them. Closely. I talk to each and every one of them. I’ve been with them for all these years. And we share the same … issues So, we have a kind of bond. Our experiences forge this kind of bond They trust me. So, they end up telling me all these things. But NOT my supervisor. So, at the end of the day. It’s a little stressful. It’s a little challenging. Working in the HIV field? No, it’s not easy… But, it’s worth it. So, at the end of the day After calling 100 people. I am left with all of their issues All of their unresolved issues. Jen told me, “I’m sick, just got surgery.” Alice told me, “I don’t have food in my house.” Rose told me, “My boyfriend kicked me out.” Millie told me, “Like my kids, they run out of the house.” I appreciate that they are sharing their lives with me. That they trust me But on the other hand, I tell myself, “How can I help these women? I have my OWN issues here!”
I’m hearing all these stories,
But I’m not a counsellor.
So, I can’t advise them.
I’m learning about all of their concerns,
But I am not a social worker.
I can’t help them.
At the end of the day
I become the keeper of all of their stories
100 stories
Including my own.
Me having my own issues
And having to deal with other people’s issues.
It IS stressful.
It IS challenging.
It can be ... depressing.

Working in the HIV-field?
No, it’s not easy...
But, it’s worth it.
I care
Because we care
For each other.

It’s not easy... but it is worth it, Miriam

In my conversations with Miriam about her work in the HIV sector, what resonated was the emotions that emerged throughout our discussions. I remember less the words that were said, and more the feelings expressed. The laughter. The anger. The tears. The joys. The hope. As Miriam spoke about her work in the HIV sector, I witnessed how this emotional work was embodied and expressed in her sensemaking of her HIV-related work. In Miriam sensemaking of HIV-related employment as emotional work, I began to grapple with the myriads of meaning that emotional work could have for African women living with HIV, and what that could mean for caring work in the context of HIV.

Miriam’s entry into HIV-related work began in Canada. Though she was aware of HIV and homeland responses to the epidemic, she did not desire to participate in response activities until
she came to Canada. In the brief talks about HIV in her homeland, she unearthed painful emotions about her personal experiences with HIV. It was those personal experiences that made her avoid HIV-related engagement in her homeland; yet through her participation in response activities in Canada, she became increasingly aware of the importance of her engagement as an African woman living with HIV. Through her friends, she was introduced to Ontario’s HIV responses as a service user. As she received information and support at AASOs, she found the experience “welcoming”:

Yeah. Well. The way I got into the HIV field was through friends who referred me to organizations. When I joined those organizations, I was welcomed as a person living with HIV. I was welcomed, I was helped, I got help. I got comfort. I got advice. And I felt I should give back. And then I started volunteering. — Miriam

Miriam found the organizational response to HIV in Canada engendered a sense of being cared for: access to information, emotional support, referrals and recommendations, and connections with other people living with HIV. From her experience of being cared for, Miriam also felt the need to “give back”. For Miriam, voluntary service within an AASO for which she was affiliated became her giving back to the response as large.

Initially, it wasn’t her intention to seek employment within the HIV sector. When she first arrived in Canada, she had found employment in a different field. At a time when she was looking for work, an opportunity came for a temporary paid position in an AASO. She was offered contractual employment coordinating an intervention project at an agency where she was volunteering. Though the contract was brief, the experience itself inspired her to continue giving back professionally to people living with HIV. At the time of our interview, she was attending school such that she could someday work in the broader health sector.
Throughout our conversations, Miriam told me that she was “passionate” about her work in HIV responses. As she discussed her work engagement as a volunteer and employee, she narrativized her passions. She demonstrated a “love” for her coordination work and affection for the women she encountered. She expressed confidence that her future work in healthcare would promote HIV awareness outside of the HIV sector. She was emotionally expressive throughout our conversations - snapping fingers and hitting the table to emphasize her points, or sitting back in her chair and crossing her arms when her points were made. She embodied and expressed her passion for her work in HIV responses, and she emphasized she would continue HIV-related work whether she was financially remunerated or not.

Yet, she also expressed other emotions: overwhelmed by the stories of the women she encountered; resignation that the African women living with HIV that she met “lose so much in life”; sadness stemming from her past that became present in the work. In Miriam’s narrativization of her work, she also embodied and expressed its emotional labour and the impacts that such work had on her. Sometimes that emotional work fueled her passion; other times she seemed emotionally overwhelmed by the labours of her caring. What resonated in Miriam’s stories of working in Canadian HIV responses is that despite her passion for the work, the work anguished her as well. Yet that pain also galvanized her passion and forged a sense of belonging to the women with and for which she worked. The relational nature of her work also made the emotional work and its labours more salient for she was working with and for women who had similar experiences as her. As African women. As immigrant women. As women living with HIV. For Miriam, HIV-related work was not easy; however, its uneasiness, including its emotional labour, for her, was worth it.
“It’s not easy…”: The emotional labour of professionalized care work for African women living with HIV

Working in the HIV field is not that easy
As a person living in this situation you experience some challenges.
I’m tasked with calling the women for our group
I call every lady to inform them of the meeting as a reminder.
And most cases when I call, they start telling me Their issues.
I say, “Hello, how are you?”
They say, “Well, you know,
This is what has been going on.”
“I have issues with my medication.”
“I have issues with my children.”
“I have issues with my boyfriend.”
“I have issues with my husband.”
So it’s an ongoing drama.
But not an intended one.
It’s something that they cannot avoid.
It’s part of life.
And it is not just HIV related, you know.
It’s everyday issues that everyone has.
Everywhere.
But there is also HIV.

Passage from It’s not easy... but it is worth it, Miriam

Miriam reminded me that work in the HIV sector “is not that easy” for African women living with HIV as they may consistently be caring for other people who share similar experiences as them. While emotional labour is commonly experienced by individuals who work in social service fields, what Miriam emphasized in her sensemaking of this unease is the three-fold emotional labour of HIV-related work for African women living with HIV: it’s not easy to hear the “[un]intended drama” of life; it’s not easy for a person living with HIV to listen to the “[un]intended drama” of other people living with HIV; and it’s not easy as an African women working in the Canadian professionalized space to be tasked to hear the “[un]intended drama”
The emotional labour of hearing the “[un]intended drama” of life: Interesting enough, formal care work was not an intended expectation of her work role. In Miriam’s role as a project coordinator, her primary responsibilities were logistical: arranging meetings, and ordering food and refreshments. Before each session, she contacted participants. While this task was supposed to be a brief reminder call, Miriam spoke as if it had become an emotional check-in. Upon her introduction, the women began to tell her how they were or how they had been. This check-in often became an emotional release for many women, as they told Miriam the concerns that had arisen, which Miriam coined the unintended “drama” of life with which many African women living with HIV cope.

Although it was not Miriam’s role to provide professional support or counsel, as the first point of contact with these women, she was often tasked with listening to their stories. As Miriam’s story suggested, storytelling for professional support may not have been the original intent — the women were sharing with her what is going on in their lives — but the concerns they shared such as health issues, relationship issues, and children issues, typically required counsel, referral or support. For instance, Miriam gave examples of concerns that arose in these conversations that potentially indicated additional counselling, follow-up, advocacy or referral: medication side-effects that may benefit from health care referrals, relationship discord or abuse that may require relationship or domestic violence counselling, or issues with children that may need advocacy or legal counsel. However, this counsellor role was not easy for Miriam. Unlike others in her workplace, Miriam had not been professionally trained as a counsellor. First of all, counselling was not part of her job responsibilities. Although she could refer the women to her
supervisor whose role it was to provide counsel and referrals, there was no guarantee that the
women would share their stories in the same way they shared them with Miriam. They saw
Miriam, a woman living with HIV with similar experiences as them, as a confidant; however, in
the professional work context, Miriam became positioned as a counsellor. While it may not have been
the intention of her agency to place Miriam in a counselling role given that she does not have
that formal experience or training, her work put her in contact with social work concerns.
Because of this, she felt compelled to listen. As Miriam spoke about the stories that she heard
from women living with HIV, she started to cry. In hearing Miriam talk about the care work she
had undertaken, I witnessed the emotional toll of hearing the unintended drama of other African
women living with HIV.

In making sense of the emotional toll of Miriam’s work, I also questioned if this emotional
labour had become an expectation of her work because she was a person living with HIV in a
professional role that put her in regular contact with other women living with HIV. Though
Miriam’s position was not an official peer position, she was open about her status within her
work; many of the women whom she contacted had known her before she began this job
because of their encounters at AASOs, HIV-related events or other spaces where people living
with HIV congregate. Consequently, Miriam had established social relationships outside of the
workplace with many women living with HIV she encountered through her work. In some ways,
Miriam had become a professionalized peer: a person living with HIV who through their work in the
HIV sector had become a resource or support for other people living with HIV. Miriam
believed that her role as a professional worker, with lived experience with HIV and pre-existing
relationships with the women, allowed her to develop trustful relationships that others at her
work could not:
We were talking with my senior my, you know, my supervisor. Yeah, I would bring some issues to her. And she was like, “How come they don’t tell me?” [Oh] But it’s how it is. You have to create that trust. So they have that trust in me. So they end up telling me all these things. But at the end of the day. It’s a little stressful. It’s a little challenging [yeah] — Miriam

Sharon Bolton (2009) noted that caring work could enhance or facilitate emotional states which engender affection between the worker and the recipient of care. In Miriam’s case, she had established emotional bonds with service users through her work that seemed to stem from shared experiences of living with HIV. As I listened to Miriam, I believed that the affective states provoked through her work were also relational: the women were able to relay their experiences and Miriam identified with them because of their shared identification with HIV. Although Miriam’s professional role was not a peer one, nor counselling an expectation of her work, the women employed her counsel because of their affective and relational bonds with Miriam. As such, the women Miriam contacted tasked Miriam to care for them. Miriam’s positioning in a professional role as a person living with HIV inadvertently obligated her to care for other women living with HIV. That she knew their experiences because of a shared affiliation made it easier for other women living with HIV to see Miriam as an informal support through her formal work.

**The emotional labour of hearing the “[un]intended drama” that mirrors’ one’s life:**

In hearing the women’s unintended dramas of life, Miriam was also reminded of her own. For instance, Miriam spoke of an experience that occurred during one of the group meetings that made her reflect on similar life circumstances she had with many of the women she met through her work. Before each session, Miriam would often lay out the food. One day, she noticed that a group member, another immigrant woman living with HIV, had started packing up food in personal Tupperware before anyone else had a chance to eat. When she conversed with the
woman about her actions, the woman told her how she was taking food to assure that she could have some later; as a woman who lived in poverty all her life, taking food from meetings had become a habit. This incident reminded Miriam of her own experiences of poverty. In making sense of this experience, Miriam highlighted how the stories shared in the group continuously reminded her that she was like the others in the group despite being employed in the HIV sector. Though as an AASO employee she was positioned as a “them”, she also considered herself a “we” as a woman living with HIV. So, as an employee living with HIV, Miriam was simultaneously positioned as belonging to and set apart from the women she encountered in the group:

I am among THE GROUP. I’M WE. I’M THEM. [Umm hmm] Yep. What they feel? ((knocks on table)) I feel it. What they face? ((knocks on table)) I face it. I may not face exactly what one is facing. But I may face at least something close to that. Like I just give you an example of seeing someone taking the food and scrambling with that, and they come to you and say, “You see, I have a problem. It’s how I grew up. I never had enough. I had to scramble for my siblings and stuff. So, that thing has been following me ever since.” Then, I look back and see how I’ve been scrambling for my children all my life.

— Miriam

In some ways, Miriam’s social positioning as an employee within HIV responses set her apart. For instance, the poverty experienced by the woman about which Miriam spoke may not have been Miriam’s reality at that time. However, in Miriam’s homeland, such poverty was once her reality. Homeland experiences became commonalities that Miriam shared with some of the women she encountered in the group.

Moreover, Miriam’s work made her privy to stories of living with HIV which were like her own. The woman’s stories of scrambling for food while raising her siblings. Miriam’s experiences of struggling for food while raising her children. The relational aspects of Miriam’s work allowed her to connect to the stories of other women living with HIV; yet in relating to these experiences, she was also reminded of the issues she had to navigate. Because of the
similarity of others unintended dramas to her own, Miriam laboured with emotionally hearing stories that echoed her own life. As a person whose employment required her to work with women sharing similar life experiences, Miriam’s emotional labour seemed unique to her positioning as a professionalized peer. Despite her logistical work responsibilities, caring for other women living with HIV became her responsibilities as a WE, another woman living with HIV. She offered emotional support to the women she encountered through her work, but because of the similarity of these experiences, she emotionally laboured in caring for them.

The emotional labour of the “certain rules one must follow”: There was another emotional labour of caring that Miriam had to endure in her AASO employment: the emotional labour that comes from inaction. As Miriam spoke about the labours of her caring work, she also talked about the challenges of hearing stories she could not address. Part of the frustration stemmed from the structural aspects of the issues she heard: income insecurity or poverty, precarious housing, social isolation, intimate partner violence, and HIV- and intersecting
oppressions. What also infuriated her was the regulation of her actions because of the “rules she had to follow” as a professionalized worker in the Canadian HIV sector:

Living here, in Canada
There are certain rules I must follow

In Canada
Peer workers are trained not to personalize.
If you have a problem, I can’t give you advice.
If you have an issue, I can’t intervene.

In Canada,
If you tell me, “My husband is doing this, and this, and this.”
I would have to say, “Oh, you need to seek help. Perhaps, try to talk to him and see how that goes.”
It would be YOUR problem to deal with
That is not how I FEEL!
That’s how I have been trained.
I have to be cautious of what I say and what advice I give.
I have to be careful about the reputation that I may get.

Back home, in Africa where I was born.
If I am your peer, I am your friend.
And as your friend.
I’ll tell you exactly how I feel.

Back home,
My role would not stop me from helping.
If you tell me, “My husband is doing this, and this, and this.”
I would say, “You know what? I’m coming over there right now. Let’s go call the police and do something.”
I would take steps right away. To help you. Support you.

Even though I may have the same job.
Back home, I am free to be myself.
In Canada, there are certain rules I must follow.
In Canada.
Many of our clients live in poverty.
Dependent on social supports.
But, I can’t help them.
I’m not able to help them.
In Canada,
If you tell me, “You know what? I don’t have a meal. ODSP didn’t give me the money.”
I would tell you, “You know what? I’m on ODSP TOO! I can’t help you.”
“I have children to feed. My money can only go so far.”
Back home,
If you tell me, “You know what? I don’t have a meal.
I would say, “Come. I have bananas in the plantation.
Come take them. Come. You can share my meal.”
Even though we could be experiencing the same thing. The same poverty.
Back home, I can help you.
Here, I can’t.
In Canada, there are certain rules I must follow.

_Certain rules I must follow, Miriam_

To illustrate the “rules she had to follow” in the Canadian response, Miriam gave hypothetical comparisons of how she _could act in her homeland_ in relation to how _she had to act in Canada_ such as the address of intimate partner violence, or income precarity in both nationalized contexts. In this comparison, Miriam recognized that these problems could arise in both locales, but she believed that in Canada she was governed by restrictive rules of conduct that she was not bounded to in her African homeland. Though Miriam could not name who imposed these rules, she implicitly understood systematic rules of conduct as an employee in the Canadian HIV sector because of the perceived implications or ramification of not following the rules. For instance, Miriam recognized the autonomous culture of Canadian spaces: if in Canada, she fed a woman living in poverty, she would deplete her own limited resources. Miriam also recognized organizational values superseding personal ones in Canadian HIV-related work contexts: if in
Canada, she honestly expressed her opinions, she could earn a negative reputation at her workplace. Miriam seemed governed by rules of conduct that echoed the professional boundaries other Narrators described, boundaries where you should clearly control how you acted as an employee living with HIV. Yet, these rules seemed nationalized as well. Miriam suggested that the rules she had to follow within the workplace were Canadian rules of professionalism in the HIV sector. Rules that differed from her African homeland.

These Canadian rules of professionalism seemed counter to the cultural rules of caregiving that guided Miriam’s conduct. For Miriam, being a “peer” — someone with similar lived experience — was akin to being a friend. As a friend, she was expected to care for other people living with HIV she encountered in her work. There were also the rules of her homeland. Miriam believed that in her homeland, she would be able to intervene, to act in accordance with how she felt. In Canada however, Miriam found she couldn’t respond to her feelings, produced from affective bonds with other women living with HIV. Miriam supposed that in Canada she couldn’t personally intervene in an abusive situation; she couldn’t nourish others with her resources. Miriam believed that in her African homeland she would find a way to intervene that responded to how she really felt. In the African homeland context, Miriam response could be congruent with her affect and culture values of communal caring; yet in Canadian contexts, the institutional rules she had to follow prevented such interventions.

The institutional rules Miriam had to follow suggested an affective governmentality, where Miriam’s emotional conduct within her work was regulated both by the HIV professional context along within the Canadian culture within which her work was embedded (Sauer, 2015). For instance, institutional rules and professional boundaries of social service work can project a detached rationality: controlling how one expresses affect towards people in one’s care. As Arlie
Hochschild (2003) highlighted, emotions in formal caring work can become institutional products; work institutions — its practice guidelines, value systems, work cultural practices, and broader social systems — govern the feeling rules that influence how professional care workers express their feelings within the workplace. The professional institutional rules Miriam believed she had to follow suggested she should repress acting upon her feelings whether it was expressing indignation towards individual cases of domestic violence, or personally resolving food insecurity issues for a client. These institutional rules, however, countered the social norms of HIV and homeland cultures, where as an African and as a person living with HIV, Miriam should express her feelings and act upon them because of the experiential bonds that created affective ones.

In comparing the cultural rules of her African homeland to those of Canada, this affective governmentality became nationalized. Miriam believed the Canadian ways of caring for others in professional contexts regulated how she could enact her African ways of caring for her peers. Miriam noted that the mutual caring despite individual need — the sharing the bananas in one’s plantation despite one’s limited resources — is socially accepted in her homeland. In Canada, however, taking care of each other became “I can’t help you.” I can’t care for my peers in the ways I feel I should became the rule Miriam believed she had to follow in her Canadian workplace. Nonetheless, following these institutional rules did not change how Miriam FELT. As such, affective incongruence across cultural contexts coupled with Miriam inability to act upon her feelings through her HIV-related work became emotionally labourious.

Thus, Miriam laboured with rules of conduct that governed how she should care for other women living with HIV. These rules prevented her from acting in manners that embodied the care she would have done back home as an African woman living with HIV. For Miriam, she was left with these feelings of not acting: unable to offer advice, counsel, or support to women
service users within whom she shared emotive bonds. Though her professional work within
Canadian spaces regulated how Miriam could emotively care for others living with HIV, she
believed that as an African woman living with HIV, it was her responsibility to feel for and care for the
women with whom she worked. So, she was triply burdened by the emotional labours of caring:
the burden of hearing the unintended dramas of life, the burden of holding onto other people’s
stories that resembled her own, and the burden of not being able to care for other women living
with HIV as she would back home.

“..But it is worth it”: The emotional resourcefulness of caring for people living with
HIV

Working in the HIV-field?
No, it’s not easy...
But, it’s worth it.
I care
Because we care
For each other.

Passage from It’s not easy... but it is worth it, Miriam

While Miriam recognized the emotional labour of her work in the HIV sector, she also
considered its worth. For instance, Miriam valued the emotional bonds she made with other
women living with HIV through her work. She also derived benefits from the information she
received, such as healthcare information, advice on governmental assistance, and information on
medication. Miriam also believed her AASO employment inspired her to further her
engagement, including a pursuit of work in the healthcare sector. Although she appreciated the
income, she welcomed the non-monetary benefits of HIV-related work as well. In her
sensemaking of the value of her work — social supports, information, vocational inspiration —
she recognized the “pay” of working in the HIV sector, a remuneration that acknowledged the
benefits of income security but also held other forms of compensation. In our initial
conversations, Miriam spoke about the financial benefits of HIV-related employment; she considered her AASO’s offer of employment as “a token of appreciation” for the work she has done with the organization. Miriam was also aware that her AASO employment was short-term. A one-time grant supported Miriam's work; as such it was a temporary contract. At the time of our final meetings, Miriam was no longer a paid employee at her AASO. Though the grant has ended, the work remained, so Miriam went back to volunteering. As I remarked on this and asked Miriam about voluntarily doing work at an agency where she was once an employee, she challenged this cultural idealization of financial remuneration as a benefit of HIV-related work and reconceptualized the “pay” that derived from it, voluntary or paid:

I first started working in HIV-related work As a volunteer
And for a short time
I was employed in a paid position.
Which was REALLY GOOD.
You’re giving back to the community wholeheartedly
And at the end of the day, you get a token of appreciation.
A pay cheque.
Who doesn’t like that?

But I don’t do the work for the money

When the employment ended
I came back to the work
As a volunteer.
And I still go home with a smile on my face
Because I love what I do.
Living with HIV on your own
It’s not easy.
Some people can’t share their status with their family
Or do not know anyone else in the same situation
In my work, I can tell women
“You know what? I am facing similar issues.
I’m living with HIV.”
I am able to DISCLOSE.
And supporting other women living with HIV
Gives me the strength to move on with my life.

Every time I go to work,
I learn something new.
Whenever women come to me with questions
Or share their concerns in group
My supervisor responds,
“Ok. I’m going to bring in someone to talk about this issue.”
Then I and the other women.
WE LEARN NOW.
Questions about dentistry? (knocks on table)
She brings in someone.
About finances? (knocks on table)
Brings in someone.
ODSP? (knocks on table)
Brings in someone.
Medication? (knocks on table)
Brings in someone.
My supervisor brings us resources
And I learn alongside other women living with HIV.
I am constantly learning.
And stretching
My knowledge
My awareness
My surroundings
Myself.
But I also learn from the women
After hearing their stories.
I put them into practice.
‘Cause they teach me.
I teach them.
They learn from me.
I learn from them.
Because as much as doctors ((hits table)),
Social workers ((hits table)),
Counsellors ((hits table)) are skilled?
They don’t know the lived experience.
THEY DON’T LIVE OUR LIFE EXPERIENCE.
That’s what is most important.
Not the book information
The life lived experience.
That knowledge can help a person walk a mile.

You ask me to describe the difference
Between paid and voluntary work
For me
There is no difference.
The only difference is the money that you take home
But the challenges and the joy and everything?
It stays the same.
I wouldn’t mind being paid AGAIN
The money? It gives you a boost too.
But as a volunteer, I always give 110%
I don’t hold back
Because

THERE IS A PAY
HIV-related work
Paid or unpaid
There is always a chance to give back
Always an opportunity to help others
Always something new to learn.
The work is not easy.
It’s painful,
Stressful,
Emotional.
But,
At the end of the day
There is a pay.
Of knowledge,
Understanding,
Compassion,
Joy,
Love.
And that is priceless.

There is a pay, Miriam

In speaking about her work experiences in an AASO, Miriam identified the resources she had available to her through her workplace, including support services. Her work encouraged her to participate in mutual aid groups at the agency even though she was a paid worker. Miriam considered the support group a “freedom area” for her to share her concerns as well as to actively participate. She reflected on her group participation as seminal to her own self-care, since it gave her a chance to share what was going on in her life, seek advice, and listen to other people’s stories. Moreover, the Canadianized and professionalized “rules” that bound how she must express (or suppress) her feelings within her work, did not seem binding within the group experience. There were protocols in place to relieve her of the emotional burdens to care for others such as external resources to address concerns brought to the group, or referrals to professional counselling as required. Though there continued to be professional parameters to Miriam’s role, such as peer-professional boundaries of when to offer advice, these boundaries
also freed Miriam from feeling the impetus to resolve others’ issues. The group offered Miriam space to not emotionally labour alone.

The emotional support that Miriam received from the group also fostered feelings of belonging or being a “we” with other women living with HIV, many of whom were African women living with HIV who shared the “same/same/things” that she did. Miriam found that listening to other people’s experiences of living with HIV, those that echoed her own, enabled her to address her own emotional burdens. To illustrate this, she offered an example of the challenges of parenting older children that stemmed both from past homeland experiences of parenting and current challenges her children faced while living in Canada. In her narrative of mother-work, she highlighted how hearing the pains of other mothers supported her own self-care:

Lori: How do you find navigating caring for your kids considering the pain that you’ve gone through when you’re talking about the pain that, some of the things that you have gone through?

Miriam: Well, I talk I never get through those challenges with passion. Because if I just focus on the kids, then I’ll lose myself [ummm, ummm], if I focus on the kids. Then I’ll move back and I’ll be with my group and hear their pain. Their happiness. It helps me stand my ground. Because, I know there’s somebody out there dealing with the same situation or even harsher than I am. It helps me stand, the ground and say, “You know what? I am not the only one.” But if I just cocoon myself. You know I don’t want these problems, you know, I have my own problems. I will think I’m the only one who has problems and I may not learn from the other people around.

Lori: It sounds that the peer work that you do helps you outside of the peer work to in terms of, you use the example of parenting, but it also helps to deal with all the other things that you’re going through. [Yep] Yep. Okay —

Miriam: It helps me understand that there are people who are dealing with certain things and they can still wake up in the morning and say thank you God. And like if I wasn’t hearing about their stories. I feel like this is the end
of the day. I think I’m down. That’s not the case. That’s why we love that group because it helps you understand that, okay this is not the end of the day. Life goes on ((knocks table)), no matter what. ((knocks table))

As I listen to how Miriam navigated her parenting issues, I also heard how her participation in the group helped her work through them, and move on. Within the group, she found other women in similar situations or harsher situations that had been able to navigate them or continued thriving despite them.

Moreover, participation in the group allowed her to recognize that she was not alone, that these struggles were commonly shared amongst African women living with HIV in Canada. While she found the group experience emotionally painful, she also found it helpful. Hearing other people’s experiences and how they navigated them, helped her recognized that she could “lose herself” or “cocoon herself” by not talking about her personal struggles. Moreover, the stories of other women’s resilience, moving on in their lives despite their past and current challenges of living with HIV, poverty, and adapting to a new country, helped her devise strategies to move on such as developing a support system, getting parenting advise, and devising a plan to assure her children and her own future. Through her group participation, she learned how to address personal challenges of motherhood as an African woman living in Canada and living with HIV. Hearing other people’s emotional labours, helped her care for herself.

As Miriam narrativized why she continued to work voluntarily in an organization where she once held a paid position, she troubled the cultural divide of voluntary and paid work, socially productive and reproductive work. While recognizing the value of paid work, she also emphasized the reciprocated personal and social value of caring for people living with HIV. Moreover, she renarratived emotional labour as care work: her work although challenging, helped her heal and move on with her life.
Miriam also made sense of the payback of HIV-related employment. As Miriam shared her work experiences, she considered how her employment in HIV responses could further her work aspirations. Not only did her work bolster her emotional resilience, but it also inspired vocational change. In fact, she desired to find work that similarly challenged her, work in the health sector:

Miriam: At the moment, I’m going to school [Oh okay]. ..... 

Lori: Why health care?

Miriam: I want to work with people and I want something that is challenging.

Lori: What about health care that particularly resonates with you?

Miriam: It’s challenging. You see how I told you this group is challenging? It’s the same thing. I want to continue being challenged [Okay — ]. By understanding ((knocks on table)) other people’s lifestyle, life stories it helps me move on ((knocks on table)). By me going into the office and I’m just dealing with papers and sitting there dealing with HIV. It may not help me understand. I don’t want to take life for granted.

Lori: It seems like human challenges [yeah] are what drives you.

Miriam: I want to stay with the people. Around the people. Because that’s what I’ve been doing. And if it’s something I should continue. I never used like <health field> because of what they do? The kind of job they do? But I need to stay with the people. Understand the people. Then I appreciate myself. [Oh wow]

Throughout her narrative, Miriam spoke about experiences of HIV-related oppressions within the health sector such as misinformation about HIV transmission and denial of service. Some examples she gave included being denied dental services because she was HIV-positive, and having healthcare staff double glove or put on “hazard equipment” when conducting routine health care services. In presenting these experiences to the group, Miriam encountered
other women with similar experiences. As many of the women in the group were also African, they would also discuss the misinformation of HIV in Africa and how it shaped their encounters in Canada. In listening and sharing these stories as well as personally experiencing them, Miriam re-evaluated her employment and decided to transition from the survival employment trajectory she found herself in — working multiple jobs in various sectors to assure financial security — to employment specifically in the health sector where she could continue her HIV advocacy. For Miriam, her experiences working with and learning from African women living with HIV had been vocationally inspirational. She was able to make the connection between personal issues and systemic barriers: that issues of HIV-related misinformation and mistreatment were indicative of HIV-related and intersecting oppressions faced by African women living in Canada. Consequently, she believed working in the health sector could allow her to address these systemic barriers within healthcare settings.

As a result, her work in the HIV sector pushed her towards working outside of it. Miriam defined her future health sector employment as “working from the outside”, or addressing HIV-related issues by working outside of the HIV sector. Miriam believed her “I’m WE. I’m THEM” positioning as a practitioner-outsider while an HIV-insider, was pivotal to her HIV-related advocacy. In this work, she believed her “we” status as a person living with HIV, could educate other health care practitioners about HIV, some of whom have limited knowledge of working with people living with HIV. Miriam’s sensemaking of working from the outside, echoed the outsider-within positioning that Patricia Hill-Collins speaks of, using her positioning as a person living with HIV as a source of insight she can draw from when advocating greater HIV-related education within health care settings to address HIV-related oppressions (P. H. Collins, 2000).
While this future vocation in health seemed founded on Miriam’s emotional resilience, she also recognized that such work would not be easy. For instance, she planned to be open about her status at work with no guarantee that the HIV-related oppressions she witnessed as a service user would be mitigated once she was a healthcare employee. Moreover, she may also experience the same burdens of care stemming from her “we” belonging as a person living with HIV, once again becoming a professionalized peer that offers instrumental and emotional support. Yet as a professional healthcare worker, some of these caring responsibilities would encompass her professional role. She may also have to navigate more complex “rules to follow” such as the professional boundaries and codes of ethics of health care professions that may regulate how she enacts her feelings. Miriam could also encounter new burdens: tokenism if she is the only or one of a few staff members living with HIV and interlocking systems of oppression such as racism, ableism, xenophobia, and Canadian-centrism. For instance, at the time of our last interview, she navigated Canadian-centric education systems that required her to repeat courses she had completed in her homeland. These arising challenges could interconnect with existing ones, navigating multiple working roles as a person living with HIV, health care practitioner, and HIV advocate among others.

Yet these existing and foreseeable challenges did not discourage Miriam. In narrativizing her future vocation, the tears stopped, the tables were slapped, and the narration became political oratory. In bearing witness to her aspiration story of working as a healthcare advocate for people living with HIV, what I witnessed was hope. Hope that she could move on despite pains of African homeland past that have re-emerged in Canadian present. Hope that personal and collective struggles of parenting and poverty could be addressed through advocacy. Hope that she could circumvent the Canadian “rules she had to follow”. Hope that she had a vocational
future. In narrativizing her HIV-related work as community belonging — as a woman, as an African, as a person living with HIV — Miriam illustrated that the labours of caring were not hers alone, but shared amongst others.

**The possibility and politics of HIV caring work as emotional work.** In listening to Miriam’s experience of her employment as emotional work, I better understood both its burdens and benefits. The emotive connections with others African peoples living with HIV can draw people to the work, but it can become an additional care burden that takes its toll. In witnessing Miriam’s sadness and frustration, I could also see how the work could sometimes become painful, particularly if endured without ample emotional support. These burdens could also intersect with caregiver burden and secondary trauma, particularly if the professional caregiver provides support to those enduring similar life concerns (Poindexter, 2006). Moreover, the affective governmentality that regulated how an employee with HIV can feel within the work could become an additional emotional burden. For African women living with HIV, the multiple cultural contexts that govern affect — such as homeland, HIV, and professional cultures — could be difficult to navigate. Miriam became frustrated with how her feeling acts for other people living with HIV were incongruent with the professional ways of caring practised within her Canadian workplace.

Despite its burdens, Miriam stories of HIV-related work exemplified its emotional resourcefulness. The emotional labour of bearing witness to painful stories could foster a greater understanding of one’s own experience of living with HIV. It was in this resourcefulness — access to supports, learning from others’ stories — that HIV caring work became reciprocated care for African women living with HIV. Notably for Miriam, bearing witness to other people’s experiences of living with HIV fortified her own resilience, allowing her to work through her
personal concerns, find resources, and access supports, consequently becoming integral to her self-care. The complexities of emotional work within HIV caring work requires a nuanced understanding of the resourcefulness of emotional work even in work contexts that can be highly stressful and emotionally charged.

Although the financial remuneration could also be of benefit to African women living with HIV, Miriam also taught me the other ways that her HIV-related work could “pay” off. For Miriam, knowing that her personal concerns were collectively experienced and systemic encouraged her to parlay them into a new career path. In her career aspirations, Miriam aspired to be an HIV advocate “on the outside”, working to address HIV-related misinformation and oppression through her work as a general health field. Through this aspirational work, the reciprocation continued: Miriam took the teachings gleaned from her HIV-related work towards employment that could give back to HIV responses in new ways. While HIV-related employment was challenging, the emotional work offered a new lease on her life and fortified her future employment in the broader health sector.

Miriam can teach us the potential worth to HIV-related work despite some of its emotional burdens. The emotional work of the HIV sector? No, it’s not easy. Nonetheless, for many of the narrators with whom I spoke, including Miriam, despite that unease, for them, it was worth it.
Chapter 7: What Does It Mean to Work in AASOs Because She Cares? The Teachings of African Women Living with HIV (Discussion and Conclusion)

In this chapter, I offer a summary of findings or what I call “teachings” where I summarize what each Narrator can teach us about caring work in the context of HIV and work. In learning from their narrative sensemaking of HIV caring work, I intend for you to gain a better understanding of how HIV-related work can better care for African women living with HIV. The Narrators offer five teachings: Anna teaches us about activism as reciprocated caring; Norma teaches us about caring work as re-finding work passions; Naomi cautions us on the uncaring nature of HIV-related work as unsupportive labour market engagement; Nadira cautions us on oppressive nature of the success story-telling of HIV-related work; and Miriam teaches us about the worth of HIV-related work when it cares for African women living with HIV. In these teachings, we can come to a deepened understanding of HIV caring work as care-full work for African women living with HIV, and the unique ways in which they can make sense of care-full work as immigrants, Africans, women, people of African descent, and people living with HIV. We can also learn the temporal and spatial dimensions of HIV caring work as translocal care. In their narrative sensemaking of care-full work, the Narrators teach us how African women living with HIV can re-member, re-find and translocate back home through their work engagement within and outside Canadian AASOs.

This chapter also explores the epistemic and methodological teachings of Because She Cares: its adaption of performance narrative methods such that it becomes epistemically salient knowledge generation with, for and by women of African descent. In incorporating the teachings of decolonizing, anti-colonial, and transnational feminist knowers, I explore the epistemic saliency of the study’s research methods. I also highlight the study’s contribution to the Social Work and HIV fields, and identify potential limitations and future work deriving from
this study. This chapter concludes with our thoughts – the Narrators and myself – on re-memembering, re-finding, and translocating work that cares for African women living with HIV.

“WE WILL NOT BE SILENCED!”: Anna Teaches Us Activism as Reciprocated Caring

What we can learn from Anna were the varied ways that the activist “voices” of African women living with HIV are silenced … and LOUD! Anna’s voice was silenced when she was expected to conform to activism incongruent with her own perspectives, such as the depoliticized advocacy she encountered in Canadian spaces. Anna’s voice was loudest when she was able to engage in activism on her own terms. Similar to other Narrators, what allowed Anna’s voice to be loud was the collective advocacy she engaged in amongst people with whom she found senses of belonging: homeland community members with which she mobilized, African people living in Canada with similar histories of social justice mobilization, and her “sisters”, most notably African and Caribbean women with similar experiences of social silencing in Canadian spaces.

As Anna narrativized her social silencing, what resonated were the ways that Canadian spaces shut down activism that does not conform to contemporary contexts of Canadian HIV responses. Within AASOs, the shift towards professionalized workplaces silenced forms of activism incompatible with professionalized advocacy: an individualistic approach that focuses on direct HIV-related service provision. Yet, professionalized advocacy diverts attention away from social-care: the address of systemic issues and social injustices that people living with HIV navigate in their daily lives. Moreover, the professionalized environment of Canadian AASS employment segments HIV-related work. Instead of the grassroots activism born from civil society’s responses to HIV, the role of advocate becomes assigned to the professional realm: African women as AASS employees shoulder the burden of caring for others, and African
women as clients are disempowered from engaging in their own self-advocacy. Yet, this professionalized caregiving and disempowerment of clients is the antithesis of the social caring with which HIV movements were founded. HIV social caring embodies the collective mobilization and support amongst other people living with HIV and blurs the boundaries between “employee” and “client” roles, and between AASO employment and active engagement. What resonated in Anna story was also illuminated in the Narrators’ stories of activism: HIV-related activism and its grassroots mobilization has become muted, and in some cases “silenced”, within the current professionalized, depoliticized context of Canadian AASOs.

Anna and other Narrators’ stories of “silenced” activism echoed what Roy Cain (1993; 2013) forewarned: the professionalization of HIV caring work has altered reciprocation of care amongst people living with HIV. What was once a collective, grassroots civil society response framed by greater involvement and meaningful engagement amongst all civil society members, has devolved into formalized and depoliticized modes of engagement where HIV caring work responsibilizes AASO workers. Yet, in the professionalized context of AASOs, what gets silenced are the agential voices of people living with HIV. In the depoliticized context of HIV service provision, the voices of self-advocacy and collective activism amongst all people living with HIV becomes silenced.

This silencing becomes more salient for African women living with HIV as immigrants. Anna believed that the “African ways” of doing advocacy — making placards, marching to parliament, speaking out — would not be well-received in Canadian spaces. In Anna’s questioning of activating her African ways in Canadian spaces, what particularly resonated were the ways that African women living with HIV are made to feel that Canada is not their home. The migration experience alone can be a disconnecting experience for many African women.
living with HIV particularly if arriving to Canada with no guarantee of permanent settlement, or if they arrive alone, separated from their families. This disconnection is more salient when implicit expectations of belonging to Canada require that immigrants assimilate, including conforming activist practices to Canadian norms, or risk being policed (Crowley, 2005). This disconnection and fear of policing becomes heightened by implicit reminders of one’s other-ness as activists in Canadian spaces. The politics of belonging constantly reminds immigrants of their “thin citizenship” (L. L. Wong, 2008, p. 80) if their activism does not conform to Canadian civic engagement, or the tenuousness of belonging when one is not born in Canada. As Nira Yuval-Davis (2006a) emphasized, substantive citizenship is as much a process of social membership as it is civic, social, and political engagement. It requires the Canadian state to recognize the social membership of African women living with HIV who are often treated as the social other because their social location and cultural precepts may not fit Canadian norms. Anna’s sensemaking of Canada as not “our country” illuminated the social silencing of African women living with HIV as immigrants. The politics of belonging in Canadian spaces — its social ideals embedded in Eurocentric Whiteness — constantly reminded African women that Canada is not their “home”.

Yet, Anna also teaches us that there are many ways to be “LOUD” as an activist. Notably, in her participation in everyday activism amongst other women who are marginalized in Canada, Anna engaged in quiet activism (M. Alvarez & Candelario, 2001): subversive ways in which African women living with HIV collectively advocate with and for communities to which they belong. According to Marina Alvarez & Ginetta Candelario (2001), quiet activism commonly embodies culturally congruent ways of reciprocated care for women living with HIV. This communal caring assured Anna’s “African” ways of engagement continued in Canadian spaces,
and that she re-established community membership amongst people with similar experiences of marginalization in Canada. As Alvarez & Candelario (2001) emphasized, empowerment does not solely involve organized forms of activism for HIV-positive women; often, the daily acts of caring with and for others living with or impacted by HIV can become subversive activism, particularly if in these everyday acts, African women translocate homeland ways of caring from which their activism is founded. These everyday acts of caring can become everyday acts of resistance for African women living with HIV particularly if these acts inoculate and sustain them and their communities in the face of intersecting systems of oppression (P. H. Collins, 2000; Shambley-Ebron & Boyle, 2006).

What Anna can teach us is what voice — its silences and loudness — might mean in the context of caring for African women living with HIV. For Anna, voice became a metaphoric representation of reciprocated caring: realizing her senses of self and community through civic, political and social engagement. For African women living with HIV, these active processes of engagement in Canadian spaces can realize social caring that transcends geographic borders, homeland became translocated in one’s social communion and engagement with others who share homeland or regional connection, or similar experience of racialized marginalization that are circumvented through caring for each other. What I hope we can learn from Anna is that cultural ways of social caring, such as activism, can be reciprocated care for African women living with HIV. Anna implores us to create spaces that invite African women’s ways of activism within AASOs such that they and other people living with HIV can reclaim their politicized, culturally congruent ways of HIV mobilization from which their HIV caring work is founded.
“I’m Being Called by The Heart”: Norma Teaches Us Caring Work as Re-Finding Work Passions

What we can learn from Norma is a novel understanding of HIV-related work as a calling that allows us to reconsider notions of meaningful engagement espoused in the HIV sector. What may draw African women living with HIV to employment in AASOs might not necessarily stem from the principles of greater and meaningful engagement in the HIV sector. They may also be “called” to HIV-related employment for affective or pragmatic reasons.

Norma found HIV-related employment when looking for work that fulfilled her inclination to care; yet in making sense of the work that she loved, she also made sense of the ways in which work, including HIV-related employment, called to her heart. In Norma’s sensemaking of the affective call to work — the emotive call to administrative employment, the impassioned and familial call to political activism, the rights-based call to women-centered HIV frontline work — what called to her was work that empowered her to make self and social change. Though she initially considered HIV-related work an emphatic call to care for others, in Norma’s narrativization of her work back home, notably her engagement in homeland liberation struggles, what resonated was her longing for work that fulfilled her political activism and empowered her as an African woman. While this call to activist work was initially activated in her African homeland, she found ways to translocate it in the here and now: notably, addressing patriarchal privilege within HIV service provision and claiming greater service access for women who are marginalized in AASOs. In recalling how her homeland activism shaped her aspirations as a writer, Norma also illustrated how the passions that may lead people to HIV-related work could also be pursued outside of the sector.

What also resonated in Norma’s work story was that her HIV-related employment was also an economic call: a call for “survival” at a time of financial need. She needed work to assure the
care of her family. This economic invocation was exacerbated by her difficulties in finding work upon her arrival in Canada: her employment in the HIV sector was one of many calls to work she encountered as she pursued employment that was personally fulfilling, socially contributory, and financially stable. African immigrant women living with HIV can have particular challenges finding work that utilized their skills and experiences because of institutionalized oppression within workplace practices stemming from ethnicity (i.e., preference for Canadian credentials), gender (i.e., limited childcare supports for working women), HIV (i.e., limited benefits for HIV medications), and ability (workplaces that are unaccommodating to episodic and disabling aspects of HIV-related illness) among others. (Gerbier-Aublanc, Gosselin, & Grp, 2016; Premji et al., 2014; C. Worthington, O’Brien, Zack, Mckee, & Oliver, 2012). These systemic challenges may require African women to seek out work initially for pragmatic reasons that HIV-related work may fulfill because many AASOs actively employ people living with HIV. Yet, Marjorie Gerbier-Aublanc and colleagues (2016) also suggested that African women living with HIV may develop strategies within their current work to better assure their pragmatic employment is more personally meaningful. For Norma, translocating activism born from homeland experiences brought passion to her work in the HIV sector. Her call to HIV-related employment was as much a pragmatic call for secure employment as it was an affective call to pursue social justice-oriented work. Notably, she relied on the financial security of her AASO employment to strategize her passion work outside of it.

In listening to and learning from Norma’s story, I recognized that this notion of meaningful engagement in the HIV sector can extend beyond working in AASOs or engaging in HIV responses. Meaningful engagement for African women living with HIV could also mean finding work that calls to the heart whether within and outside of the sector. It suggests an evolution of
GIPA/MEPA that recognizes the unique value of HIV-related work as meaningful engagement for each individual. As emphasized by the Ontario AIDS Network (2011), the health and social transitions of HIV and its responses coupled with shifts in peer engagement requires an evolved understanding of GIPA and MEPA that recognizes the diverse ways people interpret greater involvement and meaningful engagement in relation to their own calls to work.

Norma’s story teaches us another way to make sense of meaningful work in the context of HIV, one that puts African women’s sensemaking of passion work as self-care at the center of redefining HIV-related employment as a call to work. HIV-related employment may remain meaningful work for now, until the work to which African women aspire comes to fruition. And its meaningfulness could stem from caring for other people living with HIV, caring for self through access to information, education and supports, making a social differencing, receiving an income, gaining Canadian work experience, or creating a stepping stone into aspirational employment among other reasons. Employment in an AASO may not be a vocational calling for every African woman living with HIV. For the women who can reflect upon what makes their employment meaningful for them — recalling the times and places when work called to their hearts or recognizing how HIV-related employment moved them towards aspirational work — they may better understand why HIV-related employment calls to them NOW. In discovering its personal meaningfulness, African women living with HIV may be able to derive self-care through their work.

“They Put You Down, Down, Down, For Living This Kind of Life”: Naomi Cautions Us on The Uncaring Nature of HIV-Related Work as Labour Market Engagement

What we can learn from Naomi are the potential labours of HIV-related employment for African women living with HIV. For instance, HIV-related employment like many social service
jobs is known for its precarity; while some of the Narrators were able to secure full-time employment in AASOs, many of them were working intermittently, part-time or contractually. While this offered work flexibility such as earning an income while going back to school, for others, the precariousness of their employment required them to seek other forms of financial subsistence, including government assistance. For Naomi, however, the receipt of government assistance made her feel like she was “begging”. In her homeland culture, the acceptance of financial support outside of one’s family was socially censured. This disapproval coincided with the social censure of government assistance and its recipients in Canada, where in the current neoliberal context of minimal government, the expectation is on individuals to financially support themselves through labour market participation (Rice & Prince, 2013). This social censure was particularly hard for Naomi because of idealized narrative of immigrants that she was expected to fulfill: that of the immigrant “work[ing] hard” to realize the “opportunities” of living in a “rich country” such as Canada. Yet, Naomi’s work experiences illuminated many labour market barriers such as difficulties finding financially secure, accommodating work because of the episodic nature of HIV and corresponding physical impairments such as chronic pain.

As much as Naomi wanted to live this idealized narrative of immigrants living in Canada, it was an unrealistic one as it was based on idealistic expectations of workforce participation (based on full-time secure employment) that was incongruent with the increasingly precarious nature of work, particularly for racialized immigrant women and women living with episodic illnesses (Premji et al., 2014; Vick & Lightman, 2010). This idealized narrative can be disempowering for African women living with HIV who are also faced with systematic barriers to Canadian work force re-entry (Galabuzi, 2006) — such as restrictive recognition of non-Canadian education and
work experience — and yet the onus is on them to realize work opportunities denied to them. Moreover, this idealized narrative centered on labour market participation as active citizenship, fails to recognize the other work contributions people may make to better Canadian society. For instance, Naomi’s voluntary work improved the lives of many people living with HIV. Government support programs that focus too heavily on active participation in labour markets poorly serve African immigrant women living with HIV who socially participate in other ways — such as volunteer work — but are unable to fully participate in the workforce.

This idealized narrative of immigrant workers was also centered on ableist perspective of workers, or the false notion that current labour markets foster the equitable participation of people living with episodic disabilities. Canadian workplaces continue to be unaccommodating of episodic disability, and government supports systems are financially and systematically censorious — financial clawbacks or heightened needs-testing — of people who participate in the workforce while receiving disability supports (Vick & Lightman, 2010). Andrea Vick and Lightman (2010) recommended that disability policies and programs such as ODSP should be developed through the lens of variable-ability: rethinking constructions of work, particularly the view of work as synonymous with full-time labour market engagement.

Naomi also teaches us the transnational nature of her uncaring work and its subsequent responsibilization as a transnational neoliberal worker-citizen. Naomi’s unsupportive work story was not just located in Canada; it was translocated through homeland expectations of work and caring. Naomi was continuously exposed to cultural precepts of familial caring in her encounters with homeland-based families and homeland community members she ran into in Canada. Subsequently, her care work was constituted within social expectations of her as an immigrant from the Global South: to remit her employment income earned in the Global North. In this
vein, HIV-related employment becomes transnational care work for African immigrant women: responsibilities to financially provide to African homeland-based families that are exacerbated by subnational economic inequities fueled by globalized neoliberalism (Hernandez & Bibler Coutin, 2006). Such transnational care work presumes that African women living with HIV who are embedded in the Global North should become financially independent, transnational breadwinners with minimal supports. It also encapsulates the responsibilization of African immigrant workers to mitigate the globally classed, racialized and nationalized inequities born from colonization (Zimmerman et al., 2006).

What Naomi teaches us is a nuanced understanding of HIV-related employment as transnationally responsibilized care work, and the unique challenges that African women living with HIV face as paid workers who are living with an episodic and potentially disabling health condition, and as immigrant workers who may be financially caring for homeland-based families. What this understanding of transnational care work alerts us to is the uncaringness of Naomi’s unsupportive labour on a global scale, notably the undue labour of African immigrant women living with HIV working in Canadian labour markets to globally mitigate the ableist, gendered, classed, racialized and nationalized income inequities they often face in their daily lives.

“So Please, Stop Calling [Us] YOUR SUCCESS STORY.”: Nadira Cautions Us on The Oppressiveness of HIV Success Story-telling

The Narrators also reminded me of the intersecting systems of oppression that they must navigate as African women living with HIV. What we can learn from Nadira was how oppressive discourses can be articulated in HIV success story-telling. Interestingly, HIV success story-telling have become cultural performatives of HIV responses.
As many countries have seen increased rates of testing and treatment, and declining incidents of infection and AIDS-related deaths, success story-telling has been used to promote national approaches to the HIV-response. These success stories are particularly prominent in narrating achievements in Global South countries. Uganda’s HIV success story?: HIV prevention (Parkhurst, 2002). Brazil’s success story?: universal access to anti-retrovirals (Oliveira-Cruz, Kowalski, & McPake, 2004). Cambodia’s HIV success story?: implementing a national HIV program despite financial constraints (Charles, 2006). These success stories can become national ideologies that promote state governance, its institutions and political leaders to the exclusion of the people — healthcare practitioners, community organizational representatives, rights advocates, people living with or impacted by HIV — who fought for, promoted, developed and actualized these responses into fruition. Moreover, these national ideologies are intertwined with supranational narratives: testimonies to how other Global South nations can overcome colonialism and its current effects — income inequities, resource impoverishment, war and its aftermath — to create nationalized HIV programs that echo those of the Global North.

I thought of this as I listened to Nadira’s work story as a “success story”: whose successes were being promoted, and what is being “overcome”. Notably, her AASO appropriated her career achievements in the HIV sector to promote themselves, and their successful operationalization of GIPA/MEPA in the workplace. Furthermore, they constructed these achievements as overcoming personal adversity rather than acknowledging the systemic barriers that Nadira had to navigate: single motherhood, transnational parenting, financial precariousness, arduous immigration processes, living with HIV and concomitant stressors.

What Nadira teaches us are the potential dangers of using personal narratives of HIV-related employment to promote AASOs GIPA/MEPA successes. As people living with HIV have
realized their active and purposeful engagement in all aspects of the response, their work trajectories — from patient to engaged AASO worker — have become testimonies of successful engagement (Kielmann & Cataldo, 2010). AASOs in turn have been tasked to ensure the active and purposeful engagement of people living with HIV within their organization. This task includes organizational adherence to the principles of greater and meaningful engagement of people living with HIV. Consequently, AASOs have used personal stories of PHA employment in HIV responses to demonstrate they are living up to their responsibilities: assuring the greater involvement and meaningful engagement of people living with HIV within their organizations. In this context, personal stories of working in AASO become success stories that testify not only the relevance of GIPA/MEPA principles within organizational mandates but also to the achievements of AASO and the broader regional and national responses in bringing HIV-related employment of people living with HIV into fruition.

Nonetheless, there exists tensions of personal stories being appropriated for organizational benefit. The GIPA/MEPA narrative often compels people to disclose their seropositive status; outing oneself as a person living with HIV has been framed as rights-based responses and testimonies of greater involvement and meaningful engagement (Nguyen, 2013). However, some people living with HIV may want to selectively disclose their status within the workplace; they may feel open declaration of their status is not relevant to their work if their position is not designated peer employment. In Nadira’s case, she specifically requested that her organization keep her status confidential; yet, through their success story-telling they consequently disclosed her status to everyone privy to the story. In this vein, the success story-telling of Nadira’s AASO employment became *talking technologies* that idealize the engagement of people living with HIV in
AASOs and its entrenched infrastructures, practices, and performatives (Mazanderani & Paparini, 2015).

Another danger of HIV success story-telling is that it can promote an exceptionality discourse that testifies to “overcoming” adversity. Yet in these stories of overcoming, success story-telling articulates intersecting gendered, racialized, nationalized, and HIV-oppressive stereotypes of African women living with HIV. While the success story-telling of Nadira’s story may have initially been perceived as promotional of her, it consequently articulated deficit ideologies of people living with HIV, immigrants, and people of African descent “at their worst”: impoverished, unemployed and existing on the social margins. Furthermore, this deficit ideological lens of African women living with HIV perpetuated colonized stereotype refied in HIV response narratives — the inability of sub-Saharan African nation-states, and of its people to “overcome” HIV, that their “failures” are inherent or of their own making — and the role of Euro-Western “benevolence” to assure their national or regional successes (Farmer, 2006; Husbands, 2007; Robins, 2004). In this milieu, success story-telling of African women employees living with HIV articulates colonial deficit ideologies: notably, that their failures are attributed to being Black women, African, and HIV-positive, and their achievements will come through the benevolence of Euro-Western social service systems.

The exceptionality discourse promoted in HIV success story-telling diverts our attention away from other systemic factors — employment precariousness, migration stressors, social isolation, HIV-related oppressions, racism, xenophobia — with which African women living with HIV have to contend in finding successful work in Canadian spaces. In promoting an exceptionality discourse of African women living with HIV who can overcome adversity, success story-telling diverts attention away from systems of oppression from which such
adversities stem. Instead, the success story of African women living with HIV testifies to the exceptionality of individuals who were able to prevail despite the systems of oppression they face.

What Nadira teaches us are the potential dangers of appropriating stories of African women living with HIV to testify to organizational GIPA/MEPA successes. Nadira also cautions the potential dangers of HIV success story-telling in promoting dominant deficit ideologies of people living with HIV, African immigrants and women of African descent and its racialized, gendered, nationalized, and HIV-oppressive constitutions.

“There Is A PAY”: Miriam Teaches Us the Worth of HIV-Related Work that Cares for African Women Living With HIV

The Narrators’ also illuminated the emotional aspects of HIV-related work: its burdens and its sustenance. Despite the emotional labours of working in AASO, Miriam offered many ways in which “there is a pay” to HIV-related work. In teaching us the nuanced nature of HIV-related work as emotional work, Miriam also illuminates its worth as self-care.

Miriam’s story of being an “us” and “them” as an AASO employee living with HIV emphasized the dual role African women living with HIV balance as people living with HIV who are employed in AASOs. Caring for others through HIV-related work may become a labour of love: work one loves to do because of its affective interconnections (England, 2005). It can also take an emotional toll: the secondary trauma of hearing other’s concerns, the despair of not being able to reciprocate care amongst other people living with HIV, and the frustration of following institutional rules of employee-client interactions. What I learned from Miriam was the three-fold emotional labour of HIV-related work for African women living with HIV: the
emotional toll of HIV-related work as an AASO employee, as a person living with HIV, and as an African.

Miriam made sense of this three-fold burden by narrativizing the “[un]intended dramas” of life that her clients, many of whom were African women living with HIV, had to endure. This emotionally impacted her because of her inability to act because action, such as providing counselling, were not in accordance to her work role. The emotional impact also stemmed from being privy to these stories as an African woman living with HIV who experienced the “same/same/things” that many of her clients had. Furthermore, the emotional burdens that she experienced back home became translocated in other women’s stories, such as poverty she once faced back home being realized in many of her clients’ current experiences of impoverishment in Canada. Thus, the secondary traumas Miriam endured were also translocated ones: emotional pains of Miriam’s homeland past, re-membered in her clients’ experiences in the Canadian present. Cynthia Poindexter (2006) emphasized the emotional labour women employees living with HIV may experience because of their dual identity as AASO employees and people living with HIV which can be exacerbated if they feel they are unable to seek self-care to mitigate these burdens. As Alan Tai-Wai Li (2015) and Marvelous Muchenje (2013) emphasized, this emotional labour can become particularly arduous for immigrant employees because of translocated secondary trauma or due to professional boundaries that deter informal support seeking amongst other immigrants living with HIV, who consequently may be their primary or sole supports post-migration (A. T.-W. Li et al., 2015; Muchenje, 2013).

What particularly resonated in Miriam’s story was the emotional labour of HIV-related work when African immigrant women employees were unable to affectively express themselves as they would back home. Particularly, Miriam emphasizes how the affective governmentality
within Canadian AASOs as professionalized workplaces coupled with the incongruence between African and Canadian ways of caring for one’s peer in AASOs, could become additional labours that African immigrant women must bear (Sauer, 2015). The professionalization of AASOs and its work underlies affective governmentality as formal caring work is constituted within institutional cultures of social service and health work and regulated by professional codes of ethics (Hochschild, 2003).

While Saara Greene (2013) cautioned the potential emotional toll of the institutionalization and professionalization of emotional labour within HIV-related work, Miriam highlights the additional emotional toll when African immigrant women cannot act as per their homeland cultural precepts of caring. For Miriam, it was not only governmentality of how she should feel, but how she could perform as a person living with HIV (unable to act as a peer should), and as an African (unable to act as an African woman would in her homeland) employed in a Canadian AASSO. Miriam teaches us the additional emotional labour that African immigrant women bear because of the rules they “ha[ve] to follow” as AASSO employee working in professionalized Canadian health and social service institutions, particularly as these institutional rules were often incongruent with their homeland cultural precepts of caring. For African immigrant women living with HIV, the cultural incongruences between Canadian and African homeland cultures could reverberated as a cultural loss; the inability to engage in one’s African ways of working in Canadian spaces may become emotional labours that can intersect with the arduousness of not being able to act upon one’s feelings as they would back home.

Despite the three-fold burden of HIV related work as an AASSO employee, living with HIV, who is an African immigrant, Miriam also emphasized that HIV-related work and its emotional burdens can still become worthwhile for African women living with HIV. What I learned from
Miriam is that the times where one’s work was at is most emotionally burdensome and painful could also be the moments when it becomes quite resourceful. Notably, it was the relational aspects of her work where she drew emotional resolve. Although she experienced the emotional labour of being tasked to hear the “[un]intended drama” of women living with HIV, she also drew upon this knowledge as mutual aid. She learned from their experiences — finding resources, accessing support, navigating personal challenges — which consequently became seminal to her self-care. Though she often felt tasked to provide counsel to other women because of her professional role, her work also offered resources — such as counselling referrals, support groups and supervision — that Miriam could access to help mitigate these challenges. Although she felt burdened by the emotional labour of inaction stemming from Canadian professional rules she “must follow” as an AASO employee, Miriam strategized ways to act, including pursuit of employment “on the outside” of the HIV sector that she believed would allow her to advocate for African women living with HIV.

By illuminating the nuanced nature of HIV-related work as emotional work for African women living with HIV, Miriam also teaches us the emotional payback of HIV-related work as reciprocated care. Through her work, she engendered senses of belonging with other women living with HIV, fostered communion amongst others with shared experience of back home, and gained instrumental resources through her employment. That payback was enhanced because she received emotional sustenance — informal and formal supports — through her HIV-related work. For African women living with HIV, the ability to access formal and informal supports through their HIV-related work can reduce work burdens and allow them to navigate workplace stressors. Moreover, reciprocated care amongst other people with whom African
women living with HIV engendered senses of belonging can better assure that they do not emotionally labour alone.

Miriam teaches us the potential worth of the emotional labours of HIV-related work. In making sense of her emotional labours as emotional resilience, Miriam illuminated the ways that HIV-related work cared for her. In recognizing the reciprocated benefits of caring work amongst people to which she belonged, Miriam illuminates its “pay”. As echoed in the Narrators’ stories, HIV-related work is not easy for African women living with HIV; however, when they can receive care that emotionally sustain them, HIV-related work can be worthwhile to African women living with HIV.

Re-membering, Re-finding and Translocating Care-full Work

In listening to and learning from Anna’s, Norma’s, Naomi’s, Nadira’s, and Miriam’s stories of working in AASOs because they care, I better understand the nuanced and often complex nature of HIV caring work for African women living with HIV. Particularly, they teach us the importance of HIV-related work that ensured their self-care needs — as African women living with HIV who are employed in AASOs — while they reciprocate care through their work to the communities to which they belong.

To ensure HIV-related work cared for them, the Narrators often re-membered the ways in which they were cared for: as women, as Africans, and as people living with HIV. While our conversations offered them a space to vocalize that re-membering, they also narrativized how they re-found and translocated practices of caring through HIV-related work. In this re-membering, re-finding, and translocating work that cared for them as African women living with HIV, the Narrators offer an understanding of caring work in the context of HIV as care-full work.
Care-full work heeded the potential burdens of HIV-related work and found ways of working that were personally life-affirming, healthful and meaningful.

For us to make sense of care-full work for African women living with HIV, the Narrators implore us to listen to their stories of caring work back home and its temporal and spatial aspects. In making sense of their HIV-related work as caring for them, the Narrators drew upon individual and collective memories and experiences of care through work as Africans, women, people of African descent, and people living with HIV. Many of these memories and experiences originated from their African homelands or from their engagement in HIV responses, but some emerged from their work in Canadian spaces, or through work outside of HIV responses. Care-full work articulated memories and experiences of being cared for: past and present experiences of social justice mobilizations; communion amongst other people living with HIV; fulfillment of life passions; and informal and formal resources that mitigated the stressors and systems of oppressions encountered within work. Care-full work is intertwined with sensemaking of home. In the Narrators varied sensemaking of work that cared for them, they illuminate the diverse ways in which African women living with HIV re-member, re-find, and translocate “home” through HIV-related work.

The Narrators advise us to learn the ways in which they defined and located back home. In some cases, they defined back home as local precepts and practices of social care. Back home social care was practiced as culturally relevant activism that centered around issues that impact African immigrant women living with HIV. While Narrators’ understandings of back home activism drew from local homeland experiences of HIV and its responses they were also grounded in other forms of mobilizations — such as liberation struggles, or broader civil rights responses — to social injustices faced by African immigrant women and the communities to
which they belong. The ways in which the Narrators re-membered and translocated back home as local grassroots activism was indicative of long-distance nationalization (Glick Schiller & Fouron, 2001): translocating civil participation founded in homeland contexts through HIV-related work in Canada. Often this long-distance nationalism was realized amongst other people living with HIV who had homeland ties or similar experiences of civic engagement. What we can learn from the Narrators is the ways in which their homeland experiences of civic engagement shaped how they reframed their work in Canadian AASOs as caring for them and the communities to which they belong.

Yet, the social inequities that the Narrators faced in Canadian spaces required them to develop new strategies of locating home within social care, ones that recognized the intersecting systems of oppression they faced as racialized immigrant women living with a health compromising and socially denigrated health condition. This often required them to engage in care strategies that Nadira defined as “crossing the boundaries”: subverting the boundaries and constraints imposed on them as African immigrants, women of African descent, people living with HIV, and AASO employees. For instance, the quiet activism that Anna engaged in allowed her to translocate homeland ways of caring that were politically subversive, troubling the boundaries between professional and personal. Norma translated teachings of anti-oppressive advocacy born from liberation struggles to her advocacy amongst women living with HIV, crossing the geographic boundaries of social justice mobilization born from local homeland struggles. Nadira found ways of working amongst African, Caribbean and Black people living with HIV that troubled the deficit ideologies of people living with HIV, immigrants, and women of African descent thereby resisting intersecting systems of racism, sexism, and HIV-oppression, and pushing against its subsequent barriers. The Narrators devised strategies of anti-oppressive
self-advocacy and social activism that troubled and sometimes defied social boundaries of their perceived “otherness” within the contemporary, depoliticized context of their HIV-related work, and the broader Euro-Western supremist culture of Canadian society. In this “crossing the boundaries”, the Narrators implicitly and explicitly re-membered their oppositional consciousness born from experiences of oppression and re-found varied strategies of mobilizations (Mansbridge, 2001). In crossing the boundaries, the Narrators defined activism on their own terms for the local contexts in which they were embedded. They refined and sometimes translated back home care strategies for Canadian spaces and resourcefully drew from past and current experiences of oppression to mobilize and enact social betterment for marginalized communities to which they belonged.

The Narrators also defined back home as emotional resources that allowed them to re-find and translocate work that cared for them. The resources they drew upon included memories, practices, activities, places and spaces when work felt “good”, made a “difference”, fulfilled a “passion”, or “took care” of them. Homeland histories and memories featured heavily in work that cared for them including homeland experiences of work that “called” to Narrators’ hearts. While the affective dimensions of back home could also bring about pain and senses of loss, these painful memories could also become sources of insight for African women living with HIV, allowing them to re-frame painful experiences differently from memories past.

The Narrators also found work that cared for them through establishing relationships amongst people who became their “home”. They established mutual aid amongst people living with and working in HIV who also desired to collectively care for each other. While people from their homeland or the broader sub-Saharan African region were often members of their home communities, they also found home through the mutual support and belonging amongst people
who had similar experiences of “being silenced” in Canadian spaces, such as women living with HIV, racialized immigrants or peoples of African descent. Re-establishing home communities amongst people with similar experiences of marginalization, social exclusion or silence can aid African immigrant women living with HIV navigate intersecting oppressions encountered within their daily lives.

For some Narrators, the best way to place-make home was to leave the HIV sector entirely. This required them to re-member was home felt like and to find work that rekindled that feeling. For Norma, she drew upon the aspect of work that called to her heart; she aspired towards work she was once passionate about. For Miriam, she drew upon the “pay” she received in her communion with other African women living with HIV; she aspired towards work that allowed her to give back what she had received from these relationships. For African women living with HIV, re-kindled home can help them discover personal passions whether they originated from homeland past or recently identified from work experiences in Canada.

Narrators’ re-membering, re-finding and translocating home through their HIV-related work was evocative of bell hooks (1990) notion of home-place. For hooks, memories of home-place were resourceful: one goes back to past experiences of home-making in order to re-make home across time and place (hooks, 1990). Translocating home-place through HIV-related work — drawing upon cultural practices of care and bringing it to one’s ways of work, utilizing work-related resources to support one’s long distance nationalism, or establishing social networks amongst people with shared experiences of intersecting oppression — is congruent with processes of civic engagement immigrants may engage to resist racialized and xenophobic exclusion in settler states as well as reenacting and reframing senses of belonging that are evocative of one’s homeland (J. McDonald, 2012).
While re-membering, re-finding and translocating home could serve as a resource for self-care, it can also come with some challenges. For instance, Anna illuminated how experiences of exclusion, otherness, and social policing can “silence” African immigrant women from realizing culturally relevant ways of activism. Miriam illuminated how Canadian professionalized rules may be incongruent with home ways of community care. Moreover, re-membered home is not necessarily emotionally sustaining. Homeland memories may be painful and potentially traumatizing when exposed to them through one’s work. Re-membering the “good life” one had prior to migration could make the challenges of HIV-related work as an immigrant in Euro-Western context more salient. As hooks (1990) emphasized, re-membered home is not necessarily nostalgic, it can also become psychic sites of loss and pain. As such, she offered home, not as a physical place but as an act of creating spaces of safety, resilience, and resistance; in this vein, back home becomes more than a memory of the past or of one’s homeland but as a psychic, emotional, cultural and relational process of recreating care. It can exist through narrative process of re-membering, in connecting with other who have similar experiences or understandings of home, or experiences that foster belonging and inclusion. In this milieu, back home becomes agential practices of re-membering, re-finding and translocating care and in these agential practices, African women living with HIV can devise forms of work that cares for them.

**Because She Cares’ Contributions to the Field**

Guided by the women of African descent who advised and participated on *Because She Cares*, I discovered culturally responsive approaches to research grounded in the ways in which we — the Narrators and myself — knew our social worlds. Particularly, the Narrators guided me towards using epistemically salient methodologies and methods that elevated their voices as knowers. I had to deeply delve into the teaching of decolonizing, anti-colonial and transnational
feminist thoughts; not only to learn these theories, but to put them into practice. More importantly, this dissertation challenged me to get in touch with my embodied, emotional, and sensorial knowing, particularly the discomfort I was experiencing as a person of African descent engaging in doctoral knowledge generation in a Canadian School of Social Work and how I could use that discomfort as a knowing space.

In this section, I would like to discuss the epistemological and methodological contributions of Because She Cares. I begin by framing how this doctoral work speaks to the decolonizing, anti-colonial and transnational feminist bodies of thoughts. Next, I discuss its contribution to the Social Work field and Canadian HIV-research. I end this section discussing study limitation and future work that can derive from this research.

**Contributions to Decolonizing, Anti-colonial and Transnational Feminist Knowledge Generation.** I would like to share how Because She Cares contributes to the decolonizing, anti-colonial and transnational feminist fields. While these contributions are not mutually exclusive, I will present what I learned from each body of thought, then how this work contributes to their existing conversations on knowledge generation.

The teachings of anti-colonial thinkers alerted me to the contemporary colonial relations constituted within knowledge generation such as who produces knowledge about African women living with HIV and what such knowledge generation can do. This body of thought pushed me to not only use my Ph.D. research to document, but also to envision (and strive to enact) socially just knowledge generation. In my approach to socially just knowledge generation, I unabashedly took a political stance. I overtly positioned myself as a person of African descent, so I could introduce the reader to my understanding of knowledge generation as an outsider-within (P. H. Collins, 2000), an insight stemming from my own experiences of oppression within
academic spaces. This politicized subjective stance allowed me to be tangibly aware of the ways in which knowledge generation can epistemically and discursively mis-represent, disparage, violate, erase, and silence African women living with HIV.

I also used my privilege positioning as an academic to create space for African women living with HIV to “BE LOUD”. I used knowledge generation methods that positioned the women I interviewed, the Narrators, as central to my interpretive sensemaking of HIV-related work as caring work. I also used my doctoral dissertation to promote methods — knowledge gathering using oral traditions, poetic transcription and representation — that are not as common in Euro-Western academic knowledge generation but are common in many African descendent cultures. My intent is that in academically publishing my methodological approach and later promoting them through community-based knowledge mobilization, I “cross the boundaries” commonly imposed between academic and community knowledge generation.

The teachings of decolonizing knowing guided the path towards decolonizing my knowledge generation. Principally, I used decolonizing knowledge to assure the topical and epistemic saliency of my research. For topical saliency, I aimed for reciprocal appropriation of knowledge generation (Chilisa, 2012). My dissertation generated knowledges that have utility and applicability to the ACB strategy in Ontario and gave back knowledge generated from the study to African, Caribbean and Black communities working in Ontario HIV responses.

For epistemic saliency, I selected methodologies and methods grounded in the cultural standpoints of people of African descent. In recognizing the trialectic space of knowledge generation (Dei, 2012b), I promoted ways of knowing that were ontologically and epistemically centered in the ways in which the Narrators and myself knew our social worlds. This epistemic salient approach is a political stance as well. In taking this decolonizing approach to knowledge
generation, one that learns methodology and method from people for whom this research is
with, by, and for, I acknowledge that the ways in which we generate knowledge as researchers is
very much relational whether we admit to it or not. Too often, academics choose to position
African women living with HIV as subjects for observation. Yet, in this distance perspective,
researchers treat African women living with HIV as disembodied data, making observations
disconnected from the people who shape our interpretation (Conquergood, 2002). In this
disconnection, it becomes too easy for academics to not see participants as contributing to what
they know, or for researchers to claim interpretation as their own. In this milieu, knowledge
generation from a distance perspective becomes inhumane, unreciprocated appropriation.

Because She Cares’ decolonizing approach to knowledge generation revels in the intimacy of
knowledge generation. In this intimacy, I learned from the Narrators and recognized their
contributions to the research methods used in this study. Participative methods such as
workshopping poems are methodological approaches to intimate knowledge generation. Yet, my
intimate approach also recognizes the relational aspects of knowledge generation — talking with
Narrators off tape, gathering their thoughts as they witnessed their poetic retellings,
collaborating on a knowledge mobilization plan — and how they became seminal to
interpretations and reflections. In my multiple engagements with the Narrators, and with their
oral narratives, I became increasingly aware how these ten women transformed knowledge
generation for this study and me as a knowledge generator. So much so, I used words like
“bearing witness” “resonate” and “retelling” to name how listening to and learning from the
Narrators not only shaped my interpretations, but shape me, and shifted my understanding of
HIV-related work and of knowledge generation. I call this shifting and shaping “co-knowing” to
acknowledge this shared sensemaking process of performance narrative methods as decolonizing my knowing.

The teachings of transnational feminist thinkers implored me to look beyond the Western eye of knowledges including the theoretical and topical knowledge from the HIV, work and caring labour that I incorporated in this thesis. *Because She Cares’* contribution to transnational feminist bodies of thought is theorizing and applying translocality, and translocal intersectionality to Canadian HIV research, and its knowledge generation. Translocal theorizing allowed me to be attentive to the Narrators sensemaking of place. Translocal intersectionality allowed an interpretation of time and place in my understanding of systems of oppressions and their translocation in narratives of HIV, work and caring labour.

Translocal consciousness coupled with decolonizing, anti-colonial knowing made me more mindful of my Western centrism, its power relations and how it may shape knowledge generation and my interpretations of time and place as it emerged in Narrators sensemaking of HIV-related work as caring work. The teachings of transnational feminist thinkers also alerted me to my translocal consciousness. What I also discovered was that the teachings of decolonizing, anti-colonial and transnational feminist knowers have been part of my consciousness long before I pursued my doctoral education, as they were reflected in the communicative practices of my Jamaican heritage, the books from African, Caribbean and Black thinkers on my bookshelf, my communion with other African, Caribbean and Black knowers who communicate and relate in similar fashions, my gravitation towards participative frameworks in HIV research, and my pursuit of a doctoral degree in Social Work. Yet, I needed to re-learn them through this doctoral study such that I could recognize how decolonizing, anti-colonial and transnational feminist thoughts shaped how I made sense of my approach to
performance narrative inquiry as an epistemically salient knowledge generation with, for, and by African women living with HIV.

Ultimately, it was the teachings of women of African descent, especially the Narrators, who guided my decolonizing, anti-colonial transnational feminist approach to performance narrative inquiry. Through our research relationship, I learned how to take knowing practices from our back homes and incorporate them into academic knowledge generation. In bearing witness to their oral narrative sensemaking, I felt compelled to adapt research methods such that they illuminate the emotive, sensory and poetic resonance I experienced in the original telling. The potential catalytic impact of the Narrators stories and our poetic retelling of them necessitated that I chose work stories that resonated for the Narrators, and used methods that amplified their political, theoretical, and topical relevance. And because of our shared experiences of epistemic silencing, the Narrators persuaded me to use methods that allowed us, as women of African descent, to “be loud”: to share stories with, for, and by African women living with HIV in a manner that illuminated their wisdom, provoked critical reflection of HIV-related work as a caring practice, and evoked the sensory, emotive, embodied, dialogic and rational potential of knowledge generation from our cultural standpoints.

**Contributions to Social Work.** *Because She Cares* offers social workers an epistemically just approach to knowledge generation. Developing methodology and method grounded in the cultural standpoints of people of African descent can allow social workers to critically reflect on its relative absence in Canadian social work and the colonial power relations that contribute to its absence (Adjei, 2007). Creating space for local knowing practice can also help decenter Euro-Western supremacy in research representation (González y González & Lincoln, 2006). Putting culturally responsive research into practice encourages social workers to engage community
members in methodological development. Lastly, recognizing participants as co-knowers in knowledge dissemination can offer people of African descent greater control and ownership of knowledge produced with, for, and by them (Matsuoka, Morelli, & McCubbin, 2013).

For social workers of African descent such as myself, decolonizing approaches to social work can disrupt the alienation and disconnection we may experience in Canadian Schools of Social Work where our presence as academic scholars are relatively absent. Utilizing methodologies grounded in our cultural standpoints becomes a way for us as people of African descent to (re)find our agential voices as knowers. Such research can serve as a political stance, with us as social work academics of African descent calling out Euro-Western supremacy within academic scholarship, and incorporating Africentric knowledge systems within our own research practices (Dei, Rosenberg, & Hall, 2000). A decolonizing stance to knowledge generation not only embodies “good” research practice, but good social work practice. Decolonizing social work requires social workers to critically reflect on the knowledges produced on or on behalf of people of African descent and implores us to use research processes that challenges Euro-Western supremacy in knowledge generation and positions people of African descent as knowledge producers.

As a social worker who also works in the HIV sector, I also realize that these conversations were not just data. They were cultural teachings of work and caring labour from the standpoint of women of African descent. Their stories helped me better understand my place in HIV-related work as a Ph.D. student, community researcher, activist, Jamaican-Canadian woman of African descent, and social worker in the HIV sector. Additionally, centering the wisdom of African women living with HIV in my interpretations alerted me to my responsibilities as a social work researcher. How can I dish out the meat, marrow, and juices of these stories? How
can these stories nourish the communities impacted by them? How can I better assure that I do not malnourish the Narrators when sharing their stories to the academe? In bearing witness to the stories that flowed from the Narrators, I became alert to my relational responsibilities as a social work researcher of African descent. This relational responsibility implored me to use epistemically salient methods that have utility for other social work researchers.

**Contributions to HIV Research.** Because She Cares also responds to knowledge, methodological and theoretical gaps in the HIV field. To respond to knowledge gaps, it documents the experiences of people living with HIV — African immigrant women working in Canadian HIV responses — whose particular experiences of employment in AASOs is limitedly documented in the Canadian HIV literature. It also calls out the institutionalization of intersectional oppressions within work systems that is limitedly explored in the HIV-related work literature though a common discussion point in the transnational work literature. To respond to methodological gaps, I developed culturally relevant approaches to research with, for and by African women living with HIV that upholds stances of cultural legitimacy desired by HIV researchers of African descent. My dissertation also responds to theoretical gaps in the Canadian HIV field: it incorporates a transnational feminist lens, theorizes translocality, translocal intersectionality and translocal consciousness, and integrates knowledges from African contexts, all of which are limitedly utilized in Canadian HIV research. Because She Cares offers new understandings of HIV-related work as “meaningful engagement”, “responsibility”, “giving back”, “a pay”, “a calling” and “activism” and translocating “back home”. Study findings can
contribute to critical reflection of the cultural narratives that dominated conceptualizations of HIV-related work as self, community and social care.

**Study Limitations**

While I believe that this study can contribute to conversations on HIV, employment and PHA engagement in AASOs, I also recognize that this study and its methods have their limitations. While focusing on individual narratives allowed a more in-depth structural and thematic interpretation, it also created a small sample of narratives from which to make sense of AASO employment. There are more stories that need to be told, including the stories of other immigrant women living with HIV, including women of African descent who are not from continental Africa; we could also learn from their own local experiences of HIV mobilization as well as their unique experiences of AASO employment as women of African descent. As the Narrators stories translocated homeland experiences of HIV, focusing the study solely on women with AASO work experiences in both African homeland and Canadian contexts may have offered more transnational insights. Given that ten women were interviewed, I recognize that the narrative approaches undertaken required me to make pragmatic choices around whose stories were featured, and whose were omitted. While all the Narrators stories of work shaped my interpretation, the reader, who is only privy to five stories, does not have the same vantage point to make their interpretations. As the performance narrative methods centered on oral narrative, producing an oral dissertation (alongside the written one) was desired, but given time constraints, I was not able to do so. To rectify this, knowledge sharing/mobilization activities post-doctoral study will use performance arts methods based on oral traditions such as spoken word performance.
Some of the limitations stem from conducting doctoral knowledge generation. Originally, I had wished to apply a community-based participatory framework at the onset of my Ph.D.; however, there can be challenges with incorporating community engagement frameworks in doctoral research project as Ph.D. students are expected to demonstrate that the resulting thesis is “their” original work (Greene & Chambers, 2011). Nonetheless, it felt disingenuous to not meaningfully engage participants within this knowing process given how much I had learned from them. I also considered the potential harms of not involving the participants such as inadvertent disclosure when representing their long-form narratives into poems. As such, I revised my methods to incorporate participant engagement, such as the selection of work stories and poems featured in this dissertation; I also continue to work with the Narrators as we devise knowledge mobilization activities. Community engagement in this project, although at the later stages, was not a tokenistic gesture; it was to recognize the Narrators as co-knowers, safeguard the respectful and non-maleficence of knowledge sharing, and better assure the utility of the findings and of the methods developed.

Perhaps the most salient limitations of this study are its attempts to decolonize doctoral knowledge generation. I grappled with striving to decolonize knowledge generation given the continued Euro-Western centrism of knowledge generation in Canadian spaces. I incorporated my multiple worldviews, as an academic of African descent embedded in a Euro-Western centric settler state; and yet I grappled with doing so as an anti-colonial scholar who desired to resist the prominence of Euro-Western centrism within my ways of knowing. Yet, my Euro-Western centrism became a continual limitation of this Ph.D. As I produce a written thesis rather than an orally performed one, in English instead of the local languages of the Narrators, I wonder: is this decolonizing knowing? As I race to produce this thesis, I question: should I produce the
community products first? As I prepare for my defense, I ponder: who should be assessing my Ph.D.? Social Work academics or African women living with HIV? Though the primary aims of this project were to strive to decolonize doctoral knowledge generation, I grapple: is striving enough?

In this grappling and troubling with the ways in which I am consciously aware of my own Euro-Western centrism and its limitations, I also recognize that the ways in which I convey knowledge, as a second-generation Jamaica-Canadian of African descent who is embedded in a Canadian university is indicative of seconded sightedness of which Du Bois (1903/2006) speaks and the translocal consciousness I embody. And being conscious of the multiple ways in which I view the world — the African descendent, the Jamaican, the Canadian, the colonized, the “newcomer”, the “settler” — is part of this struggle. So, I incorporated the multiple ways in which I represent knowledge: poetic retelling, narrative storytelling, and academic prose. The knowing practices of Because She Cares while grounded in the Narrators and my own narrative culture, is also shaped by academic cultures, including (but not solely) the dominant Euro-Western culture of the Canadian academia. Some may see this (and my grappling) as troubling traditional doctoral prose; others may see it as capitulating to the academic requirements of a Canadian Social Work doctoral program. I however, see this striving as an integral process of decolonizing my mind: striving to resist Euro-Western supremacy yet recognizing that I cannot entirely escape the Euro-Western presence in my knowledge generation.

To mitigate this limitation, I discuss my grappling with and troublings of the Euro-Western supremacy in my knowledge generation in Chapter 4 to be transparent about the epistemic tensions of conducting this research. I also wrote about the moral implication of decolonizing academic knowledge generation in Chapter 5. For decolonizing knowing is a moral struggle as
well as an epistemic one. While decolonizing knowing strives to address Euro-Western supremacy, it also challenges us to live with its presence amongst the other ways in which we know, achieving what Dei calls a “multicentric perspectives” (p. 53) that does not position one way of knowing as supreme (Dei, 2015). As much as I can try, I cannot erase the Euro-Western presence entirely from my scholarship, for it is one of the ways (but not the universal or supreme way) in which I know. So I must be reflective of its presence within my multicentric perspective of viewing the social world. In speaking about the moral implication of doing decolonizing knowledge generation as a scholar of African descent embedded in the Euro-Western academe, I hope that more scholars who experiencing similar grappling and troubling — as colonized subjects and anti-colonial, decolonizing, and transnational feminist knowers — will critically reflect upon these epistemic tensions and how we can learn from them.

**Future Work**

*Because She Cares* has generated conversations on HIV, AASO employment, and caring work that has inspired additional and future work. Findings from Because She Cares warrants additional research on self-care for AASO workers which has been taken up on community-based project called Project PEER, a research project led by people living with HIV. This project explores informal and formal supports for people living with HIV who are employed in Canadian AASOs. The methods used for this study have provoked conversations on decolonizing HIV research to which I have already contributed (Chambers et al., 2017). Because She Cares will contribute to methodological conversation with book chapters on Africentric methodologies and arts-based methodologies in social work. Research findings are also being mobilized amongst African, Caribbean and Black peoples who work in Ontario HIV responses. We are strategizing how to share the poetic retellings with new audiences: AASO employers,
other immigrant communities, and people living with HIV. The Because She Cares project has opened up topical, epistemic, and methodological discussion that fulfills study aims: to prove and evoke greater reflection and action around AASO employment of racialized immigrants living with HIV. These additional and future works testify to mobilization of study findings around self-care and AASO employment, decolonizing HIV knowledge generation, and producing epistemic salient, arts-based approaches to social work research with, for and by people of African descent.

**Concluding Thoughts**

The Because She Cares study originated from my own pondering of African women working in AASOs because they cared. This pondering became a broader question of HIV-related work as caring work and its particularities for African women living with HIV who are employed in Canadian AASOs. This pondering evolved into a grappling and troubling: how to navigate this exploration so that it was culturally responsive, epistemically salient, and epistemically just social work research. In my dialogues with other immigrant women of African descent, including ten African women living with HIV who served as the Narrators on this study, I learned how HIV-related work could and should be care-full work for African women living with HIV, and how back home becomes translocated in care-full work.

Home became a continuous feature of our — the Narrators’ and myself — sensemaking of HIV-related work. Notably for me to better understand why African women living with HIV come to work in ASOs because they care, I had to re-find home as part of my translocal consciousness. Particularly, I had to re-find ways of knowing in academic spaces that were culturally responsive to the ways in which the Narrators and myself made sense of our social worlds. This required me to make sense of *methodology and method as care-full work*. I took a cautious
approach to developing methodologies for this study: consulting with other peoples of African
descent who desired culturally responsive research, and learning narrative methods from the
Narrators themselves. I also used decolonizing, anti-colonial and transnational feminist thinking
to guide me on this journey, allowing me to be mindful of the colonial practices of knowledge
generation and bolstering me to decolonize my own doctoral knowing practices.

**What Does It Mean for an African Woman to Work in an AASO Because She Cares?**

**Final Words from The Narrators**

I conclude this thesis with the final words coming from the Narrators: a poetic retelling from
the ten women who taught me how to make sense of their HIV-related work as care-full work.
Because She Cares (A Choral Poem) offers the Narrators’ advise to other African women who
may wish to work in AASOs. I used poetic representation to illustrate their narratives as a
chorus. Individual responses become a collective voice, converging into a central narrative of the
ways in which HIV-related work can be care-full work for African women living with HIV. I
included this poem as the “final words” as I think it only fitting that this project begins and ends
with the teachings of African women living with HIV who work in AASOs.
So I asked each Narrator, “What advice would you give another woman, an African woman who is thinking about doing your job in the Canadian HIV response?” This is what they said…

It can obstruct you.  
Don't let it stop you!  
Keep focused.  
**Pursue whatever you want to do.**  
It’s not like HIV is going to define YOU.  
**You define HIV.**

If you are not involved in the response  
There’s no way your voice will be heard.  
It may not be what people want to hear.  
**The more voices that are out there, the better.**

This work requires a strong heart  
You have to take in so much  
Take in the stories that others share with you.  
**Honour people’s stories. Keep them confidential.**  
**Learn from them.**

It's hard. It's difficult. It's not easy.  
**If I manage to make a change in one person.**  
Knowing that  
Means A LOT to me.  

This job is tough.  
You will never have those moments where you say  
“Oh I had an amazing day.” So.  
**Take it as it is. Enjoy every moment.**

Know that you are not inferior  
What an HIV-negative person can do, we can do.  
Maybe we can do it even better than them.  
So if you want to move up in an ASO, you can move up.  
If you want to lead an ASO, you should lead.  
If you want it, just go for it.  
**Let nothing stand in your way.**
But you have to manage expectations
Women from my homeland
When we go into a job, we would like to think
We are going to grow.
We are going to keep rising.
But in the HIV field, where our work is so specialized
**Where are we going to rise to?**

Yet, work will give you freedom.
It will, it will.
**If you know who you are.**

It’s a great feeling to work.
But...work that is rewarding
Work that doesn’t take away from you.
Work that allows you to do
Other things, live your life, not be so stressed.
**It’s a great feeling to do**
**Work that takes care of you.**

*Because She Cares (A Choral Poem)*

and “Nadira”, The Narrators of the Because She Cares Study
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Appendices

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Appendix 1: Interview Guide

General Opening Statement

This conversation will be about your experiences working in ASO or other HIV-related employment while living in Canada. It will be your opportunity to share your work stories in the hopes that your stories along with the stories of other ACB women can allow us as an audience to understand your unique experiences of HIV-related work as a woman living with HIV.

I will start by asking you an open question regarding your employment experiences. These questions may inspire you to discuss your current employment, how this work relates to other voluntary or paid work you have done in relation to the HIV response, and how this work is a meaningful aspect of your life. Or you may want to talk about your other work commitments.

I am also interested in your journey to and from HIV-related employment, and how that journey has been for you. For instance, your past work experiences back home or before you came to Canada may be important. Although I will start the interview with a question that should get us started, this is meant to be more of a dialogue between us. It is up to you how you would like to talk about your experiences of HIV-related work. You lead the conversation and I will ask questions as we go along.

Reminder:

Just to remind you of the limits of confidentiality. If you share information during this interview about harming yourself or others, I may be required by law to breach your confidentiality and reveal personal information about you. Otherwise, I will uphold the confidentiality agreement as outlined in the consent form.
Open ended interview guide:
Now let’s have a conversation about your work in the HIV response.

Tell me about your experiences of HIV-related work, paid and unpaid, when, where and how you began, and your experiences of the work. Feel free to talk about what has influenced your participation, and what such work means for you.

As this is your story, feel free to start at a point in your life where you feel it makes sense.

Potential Probes:
- Of your job positions within the HIV sector, are there any one(s) that you would first like to talk about? ______________________________
  o Okay, tell me about working as a _____________ (job noted above).

- Tell me how you started working in HIV-related work?
  o Paid or unpaid/voluntary
  o Where (back home? In Canada?)
  o What type of work?

- Tell me how did you get involved in HIV-related employment?
  o Transitions from unemployment to employment
  o Transitions from social supports to employment
  o Transitions from unpaid work to paid work

- Often when we talk about our work in HIV, we talk about community. Tell me about your experiences of community within your work in HIV either here in Canada or back home.

- I have also heard other women talk about how working in HIV has changed the ways in which they see themselves as a person with HIV, as an African/Caribbean/Black, as a woman, or as an immigrant. Tell me about how this work has changed your view of yourself as an ACB immigrant woman living with HIV.
Closing the interview

- Reflecting on your stories of HIV, work, and employment, what is the meaning of work for you?
- Where do you see your work aspirations/dreams five years from now?
- Thinking about all that you have told me today:
  - What three pieces of advice would you give another ACB woman with HIV who is thinking about engaging in HIV-related work in Ontario?
  - What three pieces of advice would you give ASOs or researchers who hire people living with HIV?
- Is there anything you would like to share about work and HIV that we have not discussed?

Thank you very much for sharing your story with me.
Appendix 2: Demographic Questions

First, I would like to ask you some demographic question related to your HIV-related work history. These will be fairly general questions and not specific to the actual organizations that you have work or are working at.

Some of these questions may repeat what I asked you earlier when determining study eligibility. However, these questions will be used as data that will help me better understand your work stories. You have the option of refusing to answer any questions that make you feel uncomfortable.

1) What is the geographic region of your homeland or land of origin/birth?

- Africa
- Caribbean
- Central/South America
- United States
- Europe
- Other ____________________
- Don’t know/Refused

2) Age: What year were you born?/How old are you? _____________________

3) How long have you lived in Canada?

HIV-Related Work History in Canada

4) What type of HIV-related employment/paid work have you had in Canada?

- HIV-research staff (e.g., researcher, research associate, research assistant etc.)
- ASO front-line staff
- ASO management/executive
- Health or Support care staff (serving HIV population)
- Other ____________________
- Don’t know/Refused

5) When did you get your first paid position in HIV-related employment?

____________________ [ask for an approximate year, or number of years working]
6) Are you currently employed in HIV-related work?
   - Yes
   - No
   - Don’t Know/Refused

7) Unpaid/volunteer work in HIV while in Canada
   a) Have you done any unpaid/volunteer work in HIV while in Canada? (e.g., volunteer at an ASOs, provide unpaid support care for a person with HIV, community advocacy for people affected by HIV?)
      - Yes (If Yes, then 7b)
      - No
      - Don’t Know/Refused
   b) What type of unpaid/volunteer work have you done while in Canada? (List Below)
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________

8) HIV-related work outside of Canada
   a) Did you ever do HIV-related work (paid or unpaid) outside of Canada?
      - Yes (If Yes, then 7b-d)
      - No
      - Don’t Know/Refused
   b) Where else/what other countries have you worked in HIV-related work? (Note if in places other than homeland)
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________
      ____________________________________________________________
c) What type of work did you do? (List Below)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

d) Was it paid or unpaid, or both?

☐ Paid

☐ Unpaid

☐ Both

☐ Don’t Know/Refused

9) Approximately how long have you been engaged in any HIV-related work (paid or unpaid; back home or in Canada)

______________________ [ask for an approximate year, or number of years working]?

Years in Canada: __________________________

Years in another country: __________________________
10) **Non HIV-related work history in Canada**
   
a) Have you done any other paid work outside of the HIV sector while living in Canada?
   - [ ] Yes (If Yes, then 8b)
   - [ ] No
   - [ ] Don’t Know/Refused

b) What type of paid work have you done while in Canada? And when? (List Below)

<table>
<thead>
<tr>
<th>Type of Work</th>
<th>How long ago?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Expectations for Because She Cares Study**

11) Why have you decided to participate on this study?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

12) What do you hope will come out from this study?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
Appendix 3: Poetic Transcription of Oral Narrative Recordings

Using James Gee’s (1985) ethnopoetic methods for oral narratives, I incorporated non-verbal communication within my transcription. The notation style used for my dissertation draws from Jeffersonian Transcription Notation used in conversation analysis (Jefferson, 2004) but incorporates modifications made for poetic transcription of narrative data as recommended by D. Soyini Madison (1993, 2011) and Catherine Kohler Riessman (2008).

Table 1: Notation for poetic transcription

<table>
<thead>
<tr>
<th>Notation</th>
<th>Description of Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>[]</td>
<td>Square brackets mark the beginning and end of overlapping speech. Overlapping speech aligned with the conversation of the other speaker.</td>
</tr>
<tr>
<td>Underlining</td>
<td>Underlining marks emphasis in intonation (e.g., changes in pitch that deviate from surrounding text). The extend of the letters/words underlined shows where emphasis has occurred.</td>
</tr>
<tr>
<td>CAPITALS</td>
<td>Speech that is spoken with great volume or intensity (e.g., shouting).</td>
</tr>
<tr>
<td>[] I can’t speak about it</td>
<td>Speech spoken with pronounce decrease in volume or intensity (e.g., whisper).</td>
</tr>
<tr>
<td>/you/know/it</td>
<td>Front slash (/) used between words when a set of words spoken together or with minimal pause as if one word.</td>
</tr>
<tr>
<td>Fab-u-lous</td>
<td>Hyphen (-) used between words when a word is spoken together with an extended pause as if more than one word.</td>
</tr>
<tr>
<td>…</td>
<td>Ellipsis mark a micropause where the length of time is noticeable but too short to measure.</td>
</tr>
<tr>
<td>(2.5)</td>
<td>The approximate duration of time in second in which an extended pause in conversation has occurred (e.g., two and one-half seconds).</td>
</tr>
</tbody>
</table>

Within poetic transcription, these breaks in conversation will be shown by separate lines.
<table>
<thead>
<tr>
<th>Notation</th>
<th>Description of Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>(sigh)</td>
<td>Single parentheses used for paralinguistic aspirations (e.g., gasps, sighs) or nonverbal expression or vocal characterizations (e.g., laughing, crying) that occurs within conversations. If the nonverbal expression occurs when another person is speaking, the person who is expressing paralinguistic communication will be noted.</td>
</tr>
<tr>
<td>((slapped hand on table))</td>
<td>Double Parentheses indicates annotation of non-verbal activity.</td>
</tr>
<tr>
<td>Yeh,</td>
<td>Commas signal a weak pause that corresponds with a continuing intonation (i.e., enunciating lists) or that the speaker has more to say to complete their thought.</td>
</tr>
<tr>
<td>Yeh?</td>
<td>Question marks signal a ‘questioning intonation or rise in the speech irrespective of grammar.</td>
</tr>
<tr>
<td>Yeh.</td>
<td>Periods signal a stopping intonation, irrespective of grammar, or whether the speaker has stopped talking</td>
</tr>
<tr>
<td>Bu —</td>
<td>An em dash indicates a cut-off in mid-speech (i.e., by another speaker) or a change in thought from the preceding text spoken.</td>
</tr>
<tr>
<td>{inaudible}</td>
<td>Curly brackets are used when the transcribed speech is unclear or in doubt in the transcript. If guessed, the speech that is in double is placed within the curly brackets. If inaudible, then {inaudible} is entered as a placeholder for the inaudible speech.</td>
</tr>
<tr>
<td>&lt;husband&gt;</td>
<td>Chevon brackets are used when speech is anonymized (e.g., narrator name, name of family members, address, workplace etc.). A more generalized term is used in lieu of the personal info.</td>
</tr>
<tr>
<td>&lt;&lt; she looked shocked at my response&gt;&gt;</td>
<td>Double chevon brackets show contextual notes that provide more background on the context of what was said.</td>
</tr>
<tr>
<td><strong>Bolding</strong></td>
<td>Bolded text shows passages that have particular resonance in narrator’s story of HIV caring work. These passages may be turned into poetic retellings.</td>
</tr>
</tbody>
</table>
Appendix 4: Examples of Poetic Transcription

Figure 1 illustrates my use of poetic transcription techniques for emphatic expression in an oral narrative. I used CAPS to emphasize that her voice rising on certain words; I underlined words when there is emphasis in intonation that that differs from the rest of the text. Lastly, I noted body language in my notes at a particular part of the interview, but did not have a chance to incorporate it in the recording as a prompt, I would add a note to describe the body language I observed (i.e., “Her body language totally changed in this passage on GIPA/MEPA”). In this case, her body language seemed to also have emotive and political resonance — her discussion of GIPA/MEPA comprised a large part of her interview — so I also noted my reflections (i.e., “I sensed her rage!”), and I bolded this passage to indicate a resonance piece of her interview (and potential poetic retelling).

I So how does GIPA/MIPA work?

R Oh! FRANKLY, if you were to ASK ME (I laughs) <<Her body language totally changed in this passage on GIPA/MIPA. I sense her rage!>> We don’t have any. [Ah. Ok.] We don’t have any. Because. That’s another issue. I think that what drives me NUTS is we don’t have GIPA/MIPA. We don’t have GIPA/MIPA. We. (clears throat) our GIPA/MIPA. Ok. The idea of the agency GIPA/MIPA is PHAs should sign up for the SPEAKER’S BUREAU (I laughs). That’s the idea of GIPA/MIPA. To me that’s bull crap. [Umm hmm!] You DON’T DO that. You don’t need me when you need to open my wounds. That’s not fair. Involve me, in SUPPORTING ME. Involve me in what programs that you’re going to do for me. That’s GIPA/MIPA. They don’t do that.

Figure 1: Example of poetic transcription of emphatic expression
Figure 2 illustrates my use of poetic transcription techniques for emotive expression in an oral narrative. In this passage, Miriam speaks about the emotional labour she engages in her HIV-related work that interconnects with her past experiences in her homeland. While sharing this with me, she begins to cry. I was able to note her emotional expression (“Here I see that you are crying.”) which leads to her describing why she is crying. But I also note non-verbal communication (i.e., sighs, crying, pauses) in brackets. I use vertical bars (|) to indicate decreased vocal intensity during this section. I also noticed that in this passage, she kept on switching from third to first person, so I noted it. As this passage seemed to have significant emotional resonance to Miriam’s HIV care work, I bolded this section.

I: Here, I see you are crying. Let me get you some tissues. I know I should’ve put the box on the table. It’s okay [It’s —

R: (crying) |It’s sad. It’s a challenge, but it is what it is.|

I: May I ask why you’re crying?

R: |I just. (pause). I just, thought about … you see when I spoke about that, the reason why I became emotional. Because (crying, voice tearful) they [we?] lose so much in life. And they keep following us? |<<Seems to switch from third person to first person.>>

I: You can’t escape the past. Yeah. [True]. Yeah.

Figure 2: Example of poetic transcription of emotive expression
Appendix 5: Examples of Poetic Retellings

To illustrate poetic transcription, interpretation, and representation, I have included an example of a data poem. “Because She Cares (A choral poem) offers the narrators’ reflections on employment in the HIV sector. Instead of a poetic retelling of one narrator’s narrative, I chose select passages within each narrator’s narrative as it responded to a question that I asked every participant at the end of the interview: “What advice would you give another woman, an African woman, who is thinking about doing your job in the Canadian HIV response?”

In the original poetic retelling, I would poetically transcribe then organize the retelling into a poetic performance as per James’ Gee (1985) ethnopoetic method (i.e., break the passages into lines, stanzas and parts as per the poetics of the oral narrative). Then I would thematically code, going through each poetic retelling and identifying stanzas that illustrated emerging themes of HIV caring work from the study that resonated amongst multiple narratives. In some cases, I specifically choose discordant poetic retellings and juxtapose them (i.e., work aspirations as unlimited as espoused by one narrator; work aspirations as limited by the nature of the HIV sector as told by another narrator) to demonstrate that African immigrant women could have divergent viewpoints of their AASO employment as caring work.

In the resulting poem, I use textual representation to emphasize the overarching messages resonating from the poem. Each stanza represents an individual’s response to the same interview question; italics are used to emphasize their advice to other African women with HIV who wish to work in the Canadian HIV sector. I use poetic representation to illustrate their narratives as a chorus. Individual responses become a collective voice that converge into a central narrative of HIV-related employment as caring labour. This poetic retelling illustrates emerging themes of HIV-related employment as self, collective and social care such as: employment as a tool to
combat stigma and discrimination, the emotional labour of HIV-related work, the opportunities
and barriers for advancement in the field, and the challenges and possibilities of caring for
oneself when caring for others through one’s employment.

To illustrate the construction of a choral poem, I juxtapose the original narrative from the
narrator alongside the retold stanza within the choral poem. In most cases, such as the 1st
retelling, I tried to adhere as close to the original narrative, but would edit for concision. In other
cases, I may draw words from other narrators if they spoke about a similar issue. In the case of
the 2nd retelling, two Narrators spoke about using their work engagement to combat stigma
and discrimination so I combined their reflections into one stanza.
<table>
<thead>
<tr>
<th>Original Narrative</th>
<th>Stanza in Choral Poem</th>
</tr>
</thead>
<tbody>
<tr>
<td>So I think ... if you are not involved there’s no way your voice is going to be heard. Yea. It may not be what people want to hear? But at least they will think about it. Yea that’s what I think. And if more voices are there then the better.</td>
<td>If you are not involved in the response There’s no way your voice will be heard. It may not be what people want to hear. The more voices that are out there, the better.</td>
</tr>
<tr>
<td>I would tell them that they should be CONFIDENT in what they want to PURSUE? And they should just REJECT this feeling of DISCRIMINATION. They should just — even though it is there, they should behave as if it’s not there and go on with whatever they want to do. Because if they can think about discrimination and stigma it hinders, it obstructs you from everything that you WANT TO DO! [Umm hmm]. Like if you want to go and ask for help somewhere and you will be like, “Eh! Where am I going to start! Because I have HIV? So they should just keep focused on whatever they want to do.</td>
<td>Stigma. Discrimination. Fear. Depression. It can obstruct you. Don’t let it stop you! Keep focused. Pursue whatever you want to do.</td>
</tr>
<tr>
<td>I think ... again. Not. Maybe I will make also to, if they help ME I will make the women or the people living with HIV without any DISCRIMINATION! Like sex orientation discrimination of us, religion, education. That also make people — stigma and discrimination. So really that one I will fight for that. And then make people to understand each other. And. To share the experiences. And to move on. Yea.</td>
<td></td>
</tr>
</tbody>
</table>

18 To view entire poem, see Pg. 310Stigma. Discrimination. Fear. Depression.