Negotiating Identities:
A Narrative Inquiry into the Experiences of People Living with HIV in Kenya

by

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Abstract

This paper-based dissertation is a culmination of my personal journey of inquiring into the experiences of people living with HIV (PHAs), a curiosity that began as a Registered Nurse caring for dying clients who were HIV positive at a hospital in Kenya in 2003. At the time, witnessing PHAs die in large numbers, due to the unavailability of life-saving medications was heartbreaking. In my work as a Registered Nurse, I cared for Solomon, whose HIV story, though silenced, was atypical compared to the stories of other PHAs on the unit I worked. As a patient who exhibited affluence and considerable socioeconomic capital based on the number and nature of visitors he attracted to his bedside, I had many wonders about who he was. Furthermore, by asking us to conceal his HIV status from his family, I became more intrigued to what I perceived to be a paradoxical life.

Intrigued by the silences, paradoxes, and complexities in Solomon's experiences as a PHA, I embarked on a journey to Canada to pursue doctoral studies in nursing. This followed an invitation by Dr. Judy Mill and Dr. Vera Caine to join a national CIHR-funded project called *A Clinical Mentorship of Canadian Nurses in HIV Care*. My involvement in this project as a research assistant greatly enhanced my understanding of ways to engage PHAs' experiential knowledge in HIV education, research, and care in line with the Greater Involvement of People living with HIV/AIDS (GIPA) principles.

After 3 years of doctoral studies in Canada, I returned to Kenya to carry out doctoral fieldwork, aware that the availability of antiretroviral medications in Kenya has significantly changed the HIV landscape. HIV infection was no longer fatal. Instead, it is now being treated as

a chronic illness. This narrative inquiry study was based at Utumishi[1], an AIDS Service Organization (ASO) that provides care and support to PHAs in western Kenya. Luanda, Atoti, Nelly, and Estero, who became part of this study, continue to be both clients and HIV lay workers at the ASO.

In inquiring into experiences of living with HIV, the social, political, economic, and personal implications of living with HIV became explicit. The participants' narrative accounts, composed from informal and formal conversations, reflections and field notes, were negotiated with the four participants. To honor their stories, these narrative accounts became dissertation chapters.

The moral and ethical implications of engaging in narrative inquiry become even more explicit to me with the evolution of my positioning as a researcher. At the start of the research, I let the research puzzle dictate my engagement with participants. With time, as the participants increasingly became involved in the inquiry, I began to shift and see my participants as co-researchers. This shift was occasioned by my willingness to be flexible and to travel to participants' worlds in order to attend to their experiences differently.

Through a sustained relational commitment to the inquiry, I comprehended how political and social discourses that story HIV as a chronic illness shape the experiences of people living with HIV. Bury's (1982) concept of illness as a biographical disruption, which has been used to describe the social process of experiencing an illness, could not fully account for the experiences that participants lived. Further, in attending to experiences of living with HIV as HIV lay workers, I explored how the GIPA principles are taken up in a donor-funded ASO. In utilizing

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[1] Utumishi is a pseudonym for the AIDS Service Organisation where I recruited participants

Lindermann-Nelson’s (1995) concept of found and chosen communities, complexities of paid and unpaid HIV work were realized. In the last chapter of this dissertation, I take a turn to consider the significance of this research and what it contributes to the body of knowledge.

Preface

This dissertation is an original work of Geoffrey Muriithi Maina. It commenced after receiving ethics approval from University of Alberta under the title *Negotiating Identities: A narrative inquiry into the lived experiences of people living with HIV*, no Pro00038493, and was approved on April 28, 2014. Additional approvals were obtained from the Institute of Research Ethics (IREC) of Moi University, No. 0001046 on 29th August 2013.

Three papers in this dissertation have been submitted to journals for consideration. Chapter 3 is a methodological manuscript entitled **Shifting relationships: Key considerations in narrative inquiry**. Geoffrey M. Maina and Vera Caine who is my supervisor are proposed authors on this manuscript.

Chapter 8 is the second manuscript, called **Exploring the meaning of living with HIV as a chronic illness in Kenya: A narrative inquiry.** In this manuscript, the proposed authors are: Geoffrey Maina, Vera Caine, Judy Mill and Randolph Wimmer. In this manuscript, I was responsible for data collection and composition of the draft manuscript. Dr. Vera Caine, as a supervisor, gave me supervisory inputs to the manuscript throughout its development while Dr. Judy Mill and Dr. Randolph Wimmer contributed to the fine-tuning of the concepts as well as editorial work.

Chapter 9 is the third manuscript entitled **Involvement of People Living with HIV in a Kenyan AIDS Service Organization.** Although the supervisor and the supervisory committee made contributions in this paper, I am the sole author.

Dedication

I dedicate this work to Tabitha, Milan, and Max for their unwavering support during my studies; and to all the PHAs whose stories I have come to honor.

Acknowledgement

This research would not have been possible without the support of diverse people who directly or indirectly contributed to this work. First, I recognize the Almighty God, through whom all grace abound and for his divine provision and health.

To Dr. Judy Mill and Dr. Vera Caine, for believing in me and giving me an opportunity to be part of the CIHR funded national project called *A Clinical Mentorship Model for Canadian Nurses in AIDS Care*. By extending this invitation, and through their guidance, I relocated to Edmonton and began my studies at the University. Through my involvement in this project, my breadth of understanding of HIV issues both in Canada and globally was expanded. I was also exposed to people and places that significantly enriched my understanding of the contemporary issues in HIV and AIDS.

To my supervisory committee; Dr. Vera Caine, my supervisor, and Dr. Judy Mill and Dr. Randolph Wimmer, the committee members, thank you for your unwavering support and for patiently guiding me through the process. The candidacy examiners, Dr. Kris Wells, and Dr. Andrew Estefan for believing in me. Daltyn Evans, a community member and Executive Assistant at HIV Edmonton for his invaluable input about the practicality of my work. I also acknowledge the external examiner, Dr. Carol Rogers for challenging me to make the intersection between gender and HIV visible.

Throughout my doctoral studies, I have been granted diverse financial support that has enabled me meet financial obligations, which includes funding by the University of Alberta through the Faculty of Nursing: Myer Horowitz Student Association Award, Numerous Faculty of Nursing Tuition waivers, Inez Poole Nursing Graduate Scholarship, MacKinnon Bursary for

international students, Faculty of Nursing One Time Funding For International Students, Verna Kennedy Taylor Nursing Award, and the Research Bursary on Men's Health**.** The Ontario HIV Treatment Network's (OHTN) Universities without Walls Fellowship provided a forum through which I networked with a wide array of community of HIV researchers. Moi University provide me with an Encore scholarship, facilitated by my friend and mentor Dr. Gene Marsh, whose love, generosity and care to me and my family has been a source of great encouragement. Also Moi University provided me a study leave to pursue doctoral studies and funds that supported my field work.

With great gratitude and indebtedness, I salute my family: Tabitha for standing with me throughout all the phases of my doctoral life, especially when there were many uncertainties in my life; for all your sacrifice and commitment. To Milan and Max, for the many questions and wonders about what I do and when I will finish school. To my larger social and spiritual communities, for the encouragement and support, and the many invitations to socialize that made me forge a sense of belonging.

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List of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretroviral Drugs
ASOs	AIDS Service Organizations
GIPA	Greater Involvement of People with HIV/AIDS
HCP	Health Care Providers
HIV	Human Immunodeficiency Virus
MIPA	Meaningful Involvement of People with HIV/AIDS
PHAs	People Living With HIV
UNAIDS	United Nations Agency for HIV and AIDS
WHO	World Health Organization

A note on the use of fonts

I have used Comic Sans font for all my personal reflections, Arial Narrow font for the field notes, *while participants interview excerpts are written in Times New Romans italicized font.*

Since most of my participants mixed English and Kiswahili in their interview conversations, in order to make the conversations coherent for non-Kiswahili speaking readers, I translated and edited this text. I have provided an example of an edited and non-edited paragraph from a transcript in which I removed redundancies for an easier read.

Original excerpt

Being a Christian, getting HIV would be unheard-of. I kept myself well knowing that if I think of getting married, I will be protected from even getting the infection. So my first born, we got with a man, who I found in the church, and this man, we got a baby boy, from our first and second year, he started to mess around with our marriage. Being Christian, we find that there is this kind of encouragement from church members and pastors of forgive and forget this was just a mistake; he is still your husband. By the way, we did the best church wedding I could remember of in my life. Therefore, I really trusted him. Nevertheless, the point is, I really trusted him and it reached a point after the birth of our first born, he decided to mess up with our marriage. Moreover, on and off, he was asking, I am sorry, I am sorry. Forgive me. Then repeatedly, then I came to realized and then I said no, because this man, the life we are living in, we are living in a life of HIV…….

Cleaned excerpt

I lived a good life as a Christian, certain that it was impossible to get HIV if you are married and morally upright. I thought that being married was a safe bet to protect myself from getting HIV. I got married in a church to a Christian man and after 2 years of marriage, we had our first baby. Soon thereafter, he became unfaithful. When I reported his unfaithfulness to the church, I was encouraged to forgive and forget, and to move on because it may well have been a mistake and that he was still my husband. I really trusted him so much, I felt betrayed that as soon as our child was born, he decided to be unfaithful within our marriage. He would come and beg for forgiveness whenever he was unfaithful. I told him that since it is risky to have extramarital affairs, it is important for us to know our HIV status as we are in the era of HIV.

Introduction to the dissertation

This paper-based dissertation is comprised of 10 chapters: two introductory chapters, three scholarly manuscripts, narrative accounts for each of the four participants I worked with, and a concluding chapter. In Chapter 1, I locate the origin of my curiosity and interest in HIV work, beginning as a Registered Nurse, caring for people living with HIV (PHAs) in a medical unit in Kenya. This interest propelled me to begin my doctoral studies in Canada where I worked as a research assistant in a Canadian National HIV Project called *A Clinical Mentorship Model for Canadian Nurses in HIV Care.* In this project, I met Alex, a person living with HIV, who challenged my thinking about the role of PHAs in HIV work. In this chapter, I provide a brief literature review on contemporary HIV issues. Chapter 2 is my account of returning to Kenya to conduct doctoral research alongside four people living with HIV. In this chapter, I highlight the experiences of beginning field work and briefly introduce the four participants, namely: Atoti, Estero, Nelly, and Luanda. In Chapter 3 I discuss the moral, ethical, and practical implications of engaging in a relational methodology using my experiences inquiring with Luanda to highlight various issues. This discussion is presented as a manuscript entitled *Shifting relationships: Key considerations in narrative inquiry.*

Chapters 4, 5, 6, and 7 are the narrative accounts for Estero, Atoti, Nelly, and Luanda respectively. In each account, I describe how I met and recruited them to the study and our subsequent conversations. Field notes, formal and informal conversations, and reflections are the mainstay of the narrative accounts.

Chapter 8 is a manuscript entitled *Exploring the Meaning of Living with HIV as a Chronic Illness in Kenya: A Narrative Inquiry*. In this paper, I focus on Atoti's experiences of living with HIV using Bury’s (1982) concept of biographical disruption. I argue that although HIV is a biographical disruption that is considered a chronic illness, it remains a unique disease due to its indeterminate manifestation and trajectory.

Chapter 9 is written as a manuscript entitled *Involvement of People Living with HIV in a Kenyan AIDS Service Organization*. In this paper, I explore how Greater involvement of People Living with HIV and AIDS (GIPA), as a framework for understanding the involvement of PHAs in Kenya, has been taken up by Utumishi, an AIDS Service Organization (ASO) where participants work as HIV lay workers. In **Chapter 10,** I conclude the dissertation by reflecting on the personal, practical, and social significance of the research.

A man is always a teller of tales,
He lives surrounded by his stories and the stories of others.
He sees everything that happens to him through them;
And he tries to live his own life as if he were telling a story.
But you have to choose: live or tell.
(Jean-Paul Sartre, 1964)

Chapter 1: Narrative Beginnings

My passion for HIV work began when I cared for people living with HIV as a nurse. I was particularly struck by Solomon, a client dying from HIV complications, whose life story contradicted the prevailing stories of the time. With many wonders about who people living with HIV are, I proceeded to pursue my doctoral work in nursing in Canada. In Canada, I was further impacted through my involvement in a CIHR-funded research project called a *Clinical Mentorship Program for Nurses in HIV Care*. Through this project, I met Alex, who wowed me with his openness and willingness to speak about his HIV status, something that was new to me. I wondered how living and telling of his HIV experiences supported the incorporation and the sustenance of his HIV identity. In this chapter, I also reflect on the literature and describe the experiences of people living with HIV. Issues of personal and social stigma, health and other challenges, and social political discourses surrounding HIV in Kenya are explored.

When an opportunity arose for me to join the clinical mentorship project[2] for nurses in HIV care as part of my doctoral work, it evoked a mixture of trepidation, anxiety, and excitement for me. I knew that I was embarking on a journey to discover a world that was both familiar, yet unknown. At the time, when I began my doctoral work, my main experiences and interactions with people living with HIV (PHAs) were clinical; a delicate and heartbreaking endeavor

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[2] A *Clinical mentorship model for Canadian nurses in HIV Care* is a CIHR funded national, community-based research project and is referred to in this dissertation as the mentorship project. The goal of the mentorship project was to develop and increase the capacity of nurses to provide comprehensive HIV care for PHAs in Canada. The principal investigators in this project were Dr. Judy Mill, a supervisory committee member and Dr. Vera Caine, my supervisor. I participated in this project as a research assistant and PhD student and I was actively involved in data collection, analysis, and dissemination.

because when I worked as a nurse in Kenya, lifesaving antiretroviral (ARVs[3]) drugs were not available.

I remember the warm morning of September 20th, 2003, my first day as a ward nurse in a medical unit at a hospital in western Kenya. The medical ward I was assigned to was not like any other I had seen before; more patients presented with debilitating acute illnesses, as well as myriads of infectious and chronic diseases. Yet it was the disproportionate representation of diseases related to HIV that stood out; tuberculosis and pneumocystis pneumonia, meningitis, and oral thrush among others. So overwhelming were the care demands created by the sheer number of patients with HIV-related opportunistic infection, that a section of the ward was designated and set aside just for them. Anyone suspected or confirmed to be suffering from HIV was consigned to this dimly lit section of the unit, located at the farthest side of the unit, away from the nursing station. The location of this section of the ward spoke volumes about what health care providers felt and knew about HIV.

One nurse was assigned to care for the patients in this section; a place that the majority of staff, even the experienced ones, dreaded to go to. Occasionally, new staff would be assigned to provide care to PHAs without adequate orientation. It did not take long before I was assigned to the section of the ward where PHAs were placed. I had heard many tales that went along with working and caring for dying PHAs. My beginning as a nurse providing HIV care coincided with the declaration of HIV as a national disaster in Kenya, a disease that claimed 6,000 lives daily (Kawewa n.d.). Hopelessness in this unit was clearly evident, yet I was uncomfortable to admit

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[3] Antiretroviral medications (ARVs) are used to interrupt HIV viral replication and thus hinder the natural progression of HIV infection to AIDS and also delay or prevent the development of opportunistic infections. Therefore, a patient on ARVs is able to regain his immunity and live a healthy life.

to myself that there was no hope left for many of them. The battle of life and death was being played out before my very eyes and each day working on this unit became a test of faith and resilience. I wondered how long I could withstand this.

My days in the HIV section of the unit began with waking the patients and preparing them for breakfast. For a majority of them, each day burdened them with the realities of the disabilities that confronted them. Even waking them up was a grim reminder of the hopeless and bleak situation. Their fixed stares conveyed resignation to whatever fate awaited them; yet they also craved empathy and understanding, begging and pleading that I would be the solution to their torment. Yet I knew that I did not possess any magical powers. I knew that there was little I could do to reverse their fate, and giving them false hope would have been an insult to my conscience. I suspected that they knew my predicament too well, having been accustomed to seeing a huge turnover as their bedfellows passed on. I poetically sum the reflection of my daily experiences and interactions with their care:

Sad as it was, to say the least
My heart sore
Seeing them ravaged
Yet how could I avenge?

Condemned by the disease, resigned to fate
No longer at ease, no longer a lie
Wondering loudly, wondering silently
With HIV, what a wiper!

Losing weight, loose stool
Coughing loud, coughing hope
Sunken eyes, sinking lives
Hopeless I was, hopeless they left.

(Personal reflection)

Getting used to seeing so many deaths was itself an unbearable experience. Knowing that my nursing care did not make any difference was heart wrenching and troubling. Every encounter with PHAs condemned me as a helpless spectator to the demise of my compatriots faster than I could count. This left an indelible mark on my life. Reflecting on these experiences sends shivers through my bones when I remember the sheer hopelessness and helplessness that my patients and I experienced.

In the course of my duty, I would often battle with loneliness and doubt in my care. Unprepared as I was as a new nurse, I was now accountable for the care of incredibly vulnerable patients. Yet, I knew that I was not prepared for the reality that I had to face. The daily witnessing of pain and agony, the overwhelming physical demands and the weariness of caring for dying PHAs was exhausting. My preparedness, or lack of it, notwithstanding, a longing to make PHAs feel loved and cared for was present; a longing to impart humanity in my care was inwardly consuming me.

Caring for the PHAs on the ward, though tiring, was not without sacred moments that were unique and perplexing. I will always remember Solomon, a middle-aged man I cared for, who stood out to me as an iconic representation of the HIV devastation in Kenya. With a stable job, an adoring wife, and beautiful young children, Solomon had what many may call a happy, successful, and fulfilled life. Knowing that he had only a couple of months to live, he asked us to conceal his HIV diagnosis and prognosis. Whenever his wife came calling, he would pretend to be asleep lest he be tormented by her interrogative questions about this strange illness that had abruptly intruded into their seemingly complete matrimony. Unfair as it seemed, I felt obligated not to share his HIV diagnosis. Yet I often wondered if his partner was also infected with HIV.

While initially admitted with pneumonia, Solomon's health drastically and rapidly deteriorated while in hospital. He developed full-blown AIDS[4], became demented, and lost cognitive and motor functions. His boss, his wife, and his relatives marveled at the speed of his downward spiraling health. To his employer, he was a promising young man seen as the hope and the future of the corporation he worked for. To his family, he was a wonderful husband and a caring father whose joy and pride was to meet the physical and financial needs of his young family. His wife would often wonder why her husband was not improving, yet she could see numerous medications that were administered to him. She would come to visit her husband every morning and spend time with him until noon; a ritual she was dutifully bound to throughout Solomon's stay in the unit. Bringing his favorite food to complement the hospital rations, her heart was broken when she saw how weak her husband had become, unable to enjoy his once favorite meal.

Although I was engrossed in numerous nursing tasks with my patients, there was not enough time to connect with them therapeutically and apart from the courtesy salutations, attend to their stories. Although I wanted to spend time with some and respond to their experiences, I was constrained by the heavy and demanding workload that denied me this opportunity. However, Solomon was a patient that I really wanted to know, his story seemed atypical of the

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[4] Acquired Immunodeficiency Syndrome is the final stage of HIV infection. People at this stage of HIV disease have badly damaged immune systems, which put them at risk for opportunistic infections (OIs). http://aids.gov/hiv-aids-basics/hiv-aids-101/what-is-hiv-aids/

way stories of PHAs were constructed at the time. In contrast to other patients infected with HIV within the unit, Solomon was an affluent, educated, influential, and successful professional.

Over time, I learned that people in his village looked to Solomon as a role model and an icon of success in post-independent Kenya. His bedside was graced with the latest novels, newspapers, and magazines, which attested to his status. Furthermore, he was the only patient that attracted a significant number of visitors on a regular basis (which perhaps spoke of his social significance and importance). Yet, there were many things that did not add up in his life. Why was he seeking care in a government facility that was resource poor, far from home, and in a workplace town when he could afford high-end care in a private hospital? What was it that attracted visitors to him? What did he think society thought of his illness? Why could he not face up to his wife? I wondered about these inconsistencies.

Even though Solomon was enjoying celebrity-like status with the number of visitors he attracted to his bedside, his wife appeared to be getting wearied by these daily sojourns and her uncooperative partner. Reluctant to leave his bedside when the visiting hours were over, she left as she came; confused, unsettled, and increasingly tired of seeing no improvement in her husband's health. She eventually demanded that he be transferred to a new hospital. I do not know what happened to Solomon. Judging from the state of his health when he left the hospital unit, the likelihood was that sooner or later he became another statistic, another HIV-related death.

Considering how devastated his wife had become due to his illness and the acrimonious nature of his discharge from the hospital, I now wonder who he was in relation to his family, his illness, and himself. If he had been able to speak to me as his nurse and perhaps to his wife, what stories of his illness would have come forth and how would we have made sense of them? These thoughts about Solomon, his hidden HIV identity, and what it meant to him and his family still overwhelm me.

Turning Towards Canada

My journey to Canada began with a simple email to Dr. Judy Mill in the Spring of 2009 inquiring about the possibilities for PhD studies at the University of Alberta. After a couple of email exchanges, Judy extended an invitation to meet her in Kisumu, a lakeside town in the western region of Kenya where she would be attending a research internship. Determined to make an impression on her as a potential doctoral student, I armed myself with my academic and scholarly credentials and made a 100-kilometer bus sojourn to meet her. Over lunch, we talked about my research interests, how they overlapped with hers, and how to move forward with my application for admission. Soon after, she introduced me to Dr. Vera Caine who was instrumental in my admission process. Drs. Mill and Caine extended an invitation to me to join a CIHR-funded project as a doctoral student; a project for which they were co-principal investigators.

Given my early experience in HIV care in Kenya during which my engagement with people living with HIV (PHAs) was restricted to providing nursing care, the thought that PHAs had the capacity to be involved in HIV education and research was striking to me. Yet it was exactly what the mentorship project[5] I was to be part of proposed to do. With a newfound

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[5] This project was entitled "*A Clinical Mentorship for Canadian Nurses in HIV Care*" (hereafter referred to as the mentorship project) and was funded by the Canadian Health Institute for Research (CIHR). In this project, PHAs acted as mentors to nurses and by sharing their experiences of living with HIV, nurses were able to appreciate deeply what it meant to live with HIV.

eagerness to comprehend how PHAs play these roles, I prepared to move to Canada in the Fall of 2010. My initial meetings with my supervisors and the project coordinator shed some light on the work I became part of. Gradually I learned more about the importance attached to PHAs in HIV research through my involvement in the mentorship project.

The first face-to-face workshop served as a launching pad for the mentorship project; bringing PHAs, nurse mentors, and nurse mentees under one roof. This meeting was a pivotal event that would shape my understanding and perception of who PHAs were in our project and inform my future engagement with them. I realized that my experiences as a ward nurse with PHAs like Solomon and others were not what I would encounter now. Soon it dawned on me that what PHAs brought to the mentorship project were their stories to live by[6] born from years of living with HIV. Over time, I also became more aware of the contextual issues that shape the Canadian HIV discourses and PHA's experiences in Canada.

With continuous engagement with PHAs through the project, the differences between PHAs in Kenya and in Canada were becoming explicit. I found Canadian PHAs confident with their HIV status, able to readily share their HIV stories, and at ease with HIV being part of them. Their spheres of involvement in HIV education, care, and research were widely acknowledged in boardrooms, classrooms, research, and advocacy networks, as well as professional work in AIDS service organizations (ASOs) in which they were involved. Yet it was the meaning of the stories that PHAs carry with them that began to influence my wonders. Who were PHAs in relation to their HIV identities and the stories that they lived and told? What did it take for PHAs to be

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[6] Stories to live by is a narrative term for narrative identity and includes dominant and mundane stories which live within us and speak to us and our experiences of engaging in the world as we traverse diverse landscapes (Clandinin & Connelly, 1998).

involved in research, care, and education? And how did PHAs negotiate their identities in order to incorporate HIV identity and derive meaning from their negotiated identities? What were the effects of continuous public disclosure of their HIV status on their self-esteem, self-concept, and body image? From the time I met Alex, a PHA mentor[7] in the project, I was drawn to his HIV story and listening to him became an insightful experience. I continue to reflect on his story, which has become the lens through which I eventually explored the experiences of other PHAs in my research inquiry. I continue to frequently return to his story, much like the memories of Solomon that continue to surface.

Twists and Turns

From my interactions with PHAs, I appreciate that the beginning point for their HIV journeys often was their HIV diagnosis, a moment that is life defining, often marked by trauma, shock, and depression, and manifested by symptoms of post-traumatic stress syndrome (Baumgartner, 2007). Being infected with HIV is mentally and psychologically traumatic, as it elicits stigma and experiences of discrimination and calls forth fear of death (Leserman, 2008; Mill et al., 2009; Plattner & Meiring, 2006). The psychological trauma associated with an HIV diagnosis affects PHAs' self-esteem, self-image, and self-concept. Subsequently, their social and physical worlds inevitably change. In addition, their ability to ascribe meaning to their lives is compromised (Leserman, 2008; Whetten, Reif, Whetten, & Murphy-McMillan, 2008).

The HIV epidemic has experienced major turning points that include isolation of the virus, redefinition of AIDS, the discovery of treatment, and sustained HIV activism. The most

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[7] A PHA mentor was a person living with HIV that willfully shared his/her HIV experiences with nurses as a way to teach them about the realities of living with the illness.

dramatic turning point for HIV as an illness was the introduction of antiretroviral medications in 1996[8] (Grubb, Perriëns, & Schwartländer, 2003). HIV activism also succeeded in making HIV a human rights issue, which was instrumental in making PHAs' struggle visible (Ayres et al., 2006). The influence of HIV infection on employment, housing opportunities, and living conditions was brought into focus through human rights discourses (Dray-Spira, et al., 2006). Once HIV became a human rights issue, PHAs were able to push for greater involvement in HIV work and for the allocation of resources for HIV research, education, and care.

At a personal level, varying turning points characterized the transformation of PHAs' lives. Being diagnosed with HIV, disclosing HIV to others, and starting antiretroviral treatment are major events that shape HIV identity and promote transformation (Braveman & Helfrich, 2001; Greeff et al., 2008). Even with a reduction of HIV mortality, due to ARV medication, HIV remains a complex illness with PHAs differently affected by biomedical, social, and psychological characteristics of the illness. PHAs still live in multidimensional and complex physical, social, and psychological borderlands that are indeterminate and often unstable (Persson, 2004).

Bumping with Alex's Stories to Live By

Alex[9], a PHA I met in the course of my work as a research assistant, shaped my understanding of how PHAs execute the Greater Involvement of People with HIV/AIDS (GIPA)

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[8] In Kenya, ARV medications were introduced officially in 2003 with administrative costs taking the "lion's share" of donor funding. It is estimated that less than 1/3 (656,000) of PHAs who qualify for ARV treatment are on these lifesaving medications (Avert 2014).

[9] Alex is a person living with HIV, who has been involved in GIPA activities in Edmonton, including the mentorship project. He is an example of what a PHA can achieve when they live and tell their stories publicly. I refer to him often because he was the first PHA I interacted closely with during my work on the project. He readily and unreservedly told his stories in order to encourage PHAs to explore their life stories. He did this by participating in body mapping and through sharing his HIV personal story.

mandate. By participating in GIPA work[10], Alex was able to reclaim his "right for self-determination and participation in decision-making that affects PHAs lives" (Ontario HIV Network, 2011, p. 13). It was also a way to grant a voice and a greater and more meaningful participation in HIV work to PHAs (UNAIDS, 2007). Close interactions with Alex shaped my understanding of how PHAs story themselves and are storied. Lindemann-Nelson's (2001) idea of *found* and *chosen* community helped me to think about how Alex negotiated the living and telling of his HIV stories to live by, countering dominant community narratives that storied him in particular ways. As an indigenous PHA struggling to overcome alcoholism and drug addiction, Alex was storied as undeserving, irresponsible, blameworthy, and lacking in moral agency due to his HIV infection. This labelling was often based on the misunderstanding of the science of HIV (O'Byrne, 2011; Rhodes & Cusick, 2002). Yet Alex chose not to be a passive recipient of dominant community narratives. He instead challenged these inferred identities by participating in ASOs as a volunteer in HIV education, research, and public speaking.

> *When I tell my [HIV] story, I talk about my pain and the struggles that I had to overcome after I was diagnosed with HIV. It dawned on me that I could not run from it any more after leading a risky lifestyle that led to infection with HIV. Although I was aware of HIV at the time of diagnosis, I thereafter gave myself to a deeper understanding of this new and strange disease that has become a part of me. The more I learned about the disease [HIV], the more I became a responsible adult and I changed my lifestyle. I stopped taking alcohol and abandoned risky sexual practices and self-medicating with drugs to numb my pains. I was fortunate to do this considering that many of the fellow PHAs that I know have died from drug overdoses and self-neglect. I did not want to go down that route and that is why I changed my lifestyle and took interest in my welfare, survival, and health.*

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[10] The GIPA principles were first proposed in 1983 in Denver, 2 years after the first case of HIV was diagnosed in the USA. However, it was not until 1994 that the GIPA principles were officially formalized in a Paris AIDS summit involving 42 countries who committed themselves to "greater support of PHAs' involvement at all levels in order to stimulate the creation of a supportive political, legal and social environment" (AIDS Committee of Ottawa, n.d., p. 1).

> *Today, I try telling other people about HIV and how to keep away from it.*[11] (Personal Communication, Alex, 2012)

Rather, through his living and telling of his life, Alex has renewed himself by resisting dominant narratives that seek to define him within HIV's chosen community. In so doing, he is able to reclaim his identities (Lindemann-Nelson, 2001) that were lost or eroded by HIV infection. In this process, he rewrites, retells and relives those stories that the *found* communities prescribe (Lindemann-Nelson, 2001). Alex, like other PHAs I have met in Canada, encounters stigma and discrimination on many levels, a constant reminder of how his stories to live by bump up against the dominant stories. As a way of reliving experiences, Alex challenged the dominant stories that misrepresent him and erroneously construct him as undeserving and reckless. While HIV infection affects body functions as well as one's capacity to engage in social roles (Tewksbury & McGaughey, 1998), the incorporation of HIV into his life guides Alex's perceptions and experiences.

The rhetoric of "I, a person living with HIV, am living with hope" (Personal Communication, Alex, 2011 and 2012) is Alex's slogan, which signals the ease with which he lives out his HIV identity. Yet to Alex, although his HIV identity is one of his many identities, it plays a significant role in how he forms his reality and living. Listening to Alex I wondered: What does it mean to assume an HIV identity? Does it mean that as a PHA, he has no choice but to accept his HIV infection? Does it mean that he has to adjust to psychosocial and biophysical changes associated with HIV and endeavor to meet the medical and social demands related to

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[11] This excerpt arises from a one-on-one interview that I had with Alex as part of a qualitative research methods course. The aim of the interview was to understand his involvement in HIV education with undergraduate nursing students at a Western Canadian university, where he shared his story and also engaged in body mapping.

HIV? For Alex, as I came to learn, living with HIV meant re-storying his life in a way that conveyed acceptance of his illness with optimism and hopefulness. It also meant that he must convey a response to challenge the stigmatizing public opinions and community discourses. To live his HIV identity also meant he must portray his willingness, capacity, and ability to story his life under the gaze of the public eye. The impact of my encounter with Alex shaped my expectation and imagination of how an emancipated and empowered PHA can make sense of stigma and discrimination. Further, it deepened my understanding of the opportunities that can and are available for PHAs to be meaningfully involved in HIV work.

What Issues do PHAs Contend with?

Until recently, when antiretroviral medications became available, HIV infection was terminal and its trajectory fatal. However, even with fewer fatalities as a result of antiretroviral medications, HIV significantly affects all aspects of people's life and alters life decisions and identities (Doyal, Anderson, & Paparini, 2009; Mosack, Abbott, Singer, Weeks, & Rohena, 2005). In addition, the severe side effects of antiretroviral medications make adhering to these medications burdensome, requiring a high level of self-discipline and motivation. PHAs may also battle with socioeconomic and health-related challenges that continuously shape their identities and experiences and affect their quality of life. Through working closely with PHAs in the mentorship research project and attending to their stories, I have come to appreciate these complexities.

Personal and Social Stigma

Despite a significant reduction in HIV mortality, PHAs continue to be subjected to stigma. Goffman (1963) describes stigma as "bodily signs that expose something unusual and bad about the moral status of the signifier" (p. 1). Stigma occurs when one possesses an unusual characteristic that is considered disgraceful by society and which becomes the focal point for discrediting and stigmatizing tendencies. In effect, the stigmatized persons lose their place and are denied full acceptance in society (Alonzo & Reynolds, 1995; Campbell & Deacon, 2006; Duffy, 2005; Goffman, 1963).

HIV stigma is a manifestation of social structures that have evolved since the pandemic began and manifests differently across cultures and geographic locations (Duffy, 2005). HIV stigma, discrimination, and silence have been described as a third AIDS pandemic due to their roles in spreading HIV infection (Mann, 1987). The complex social and cultural connections surrounding HIV make it difficult to mitigate HIV stigma (Lekas, Siegel, & Schrimshaw, 2006; Parker & Aggleton, 2003).

Further, stigma is an important phenomenon that shapes how PHAs experience their illness. The continued association of HIV infection with marginalised groups, as well as its association with sexuality, death, and poverty, compounds HIV stigma (Kit, 2009; Kit, Rungpueng, & Reidpath, 2009; Sofolahan, Airhihenbuwa, Makofane, & Mashaba, 2010). HIV stigma creates power imbalances that provide platforms for blame, segregation, labeling, and stereotyping. Subsequently, the life opportunities for PHAs are diminished (Alonzo & Reynolds, 1995; Link & Phelan, 2001).

HIV stigma may be manifested as felt or enacted (Lekas, Siegel, & Leider, 2011). Felt stigma refers to real or imagined fear of the societal attitudes towards PHAs because of the HIV infection and the discrimination that may arise from it. Enacted stigma, on the other hand, is the real experience of being stigmatized and discriminated against because of having HIV (Brown, Macintyre, & Trujillo, 2003). Enduring HIV stigma hinders HIV prevention, testing, disclosure to others, health seeking among PHAs, and safe sexual practices (Brouard, & Wills, 2006; Mill et al., 2009). Further, internalization of HIV stigma by PHAs may cause self-blame, hopelessness, fear of discrimination, and low self-esteem (Brouard & Wills, 2006; Rohleder & Gibson, 2006; Simbayi et al. 2007).

Stigma in care.

Health practitioners may be confronted with complex challenges when they interact with PHAs in care (Mill, 1997) that result in stigmatizing behaviors towards them. Just like society-at-large, health care providers (HCPs) may associate HIV infection with 'high-risk' behaviors and marginalized populations (Duffy, 2005; Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010). Nurses in particular have been known to stigmatize and discriminate against PHAs when providing nursing care, believing that PHAs are responsible for their HIV infection (Surlis, & Hyde, 2001). As a result, nurses may be unwilling or reluctant to care for PHAs due to their fear of contagion (Pickles, King, & Belan, 2009). Blame and judgment, unprofessional disclosure of client's HIV status to other colleagues, and imposing personal values on PHAs, are some of the ways nurses have been reported to stigmatize and discriminate PHAs in health care settings (Andrewin, & Chien, 2008; Tartakovsky, & Hamama, 2013). Nurses also exhibit stigma towards PHAs by using derogatory language in reference to them and deliberately breaching the confidentiality of PHAs in their care (Grindel & Patsdaughter, 2000; Surlis & Hyde, 2001).

Lack of adequate preparation in HIV care may be another driver of stigma and discrimination of PHAs by nurses. This may be due to a lack of adequate HIV care content in the undergraduate curriculas (Mill et al., 2014). Subsequently, graduating nurses may be inadequately trained to offer relevant and appropriate HIV care. Poorly equipped nurses in HIV care exhibit HIV stigma through inconsistent and inappropriate application of universal precautions including double gloving and wearing masks when caring for PHAs (Nderitu, Mill & Richter, in press, 2015; Whetten et al., 2008). In other instances, nurses have been reported to coerce people to test for HIV, test without consent or adequate counseling, while others may disclose their HIV to unauthorized people (Mill et al., 2010).

Dealing with health and other challenges.

Following the advent of antiretroviral medications, the quality of life for PHAs is closely associated with the disease progression and the socioeconomic status of a PHA (Jia et al., 2004). Socio-economic factors such as housing and employment are major determinants of how PHAs experience HIV illness and access to care. PHAs who are homeless often struggle with adherence to HIV medication and access to medical care. They are more likely to engage in risky behaviors such as trading sex for money, risky sexual practices, and substance use or sharing needles (Kidder, Wolitski, Campsmith, & Nakamura, 2007). Social support and coping with HIV symptomatology and antiretroviral medication side effects is central to improving one's quality of life (Ashton, et al., 2005; Jia et al., 2004). Further, aging with HIV and the chronic use of antiretroviral medications is causing a wide range of physical and mental disabilities and other uncertainties that compromise the quality of life for PHAs (O'Brien, Bayoumi, Strike, Young, & Davis, 2008).

Sociopolitical discourses surrounding HIV.

Due to the scale of HIV devastation, there has been a clamor to treat HIV and AIDS as an exceptional epidemic based on its uniqueness as a medical and a social illness with long-lasting demographic, socioeconomic, and political impact (Smith & Whiteside, 2010). Bayer (1991) coined the term AIDS exceptionalism by arguing that HIV is a unique disease (based on its characteristics and demographic profiles of infected people). Labeling HIV as an exceptional disease resulted in HIV receiving preferential funding. Part of the HIV exceptionalism status was attributed to activism, which increased the global investment in HIV care and research (Smith & Whiteside, 2010). Currently the debate has shifted towards treating HIV and AIDS like other chronic illnesses. With improved care due to antiretroviral medications, opponents of AIDS exceptionalism contend that HIV is excessively funded at the expense of other equally important global health concerns, which may undermine health care systems (Shiffman, 2006). For instance in 2010, $6.9 billion were raised towards the AIDS global fund (Rushton, 2011). At the same time, HIV mortality had been drastically reduced due to antiretroviral medications. Therefore, a rethinking of HIV politics to allow integration and balancing of HIV with other pressing health issues is proposed (Rushton, 2011).

Involving PHAs as educators, research participants, and caregivers requires them to overcome the effects of oppressive stigma that permeate all sectors of society. In addition, they must live with the public expectations and pressures to live and share their HIV diagnosis with others in order to use their bodies and life stories as an exhibit for HIV work. It is therefore imperative to gain an appreciation and a deeper understanding of the experiences that PHAs tell and live. To allow me to explore the experiences of PHAs in Kenya as they lived and told their HIV stories, I engaged in a narrative inquiry with PHAs who told their HIV experiences as part of their work as HIV lay workers.

This paper-based dissertation comprises of three papers found in chapters 3, 8 and 9. In chapter 2, I describe my journey to Kenya to engage in relational conversations with participants who live with HIV as part of my doctoral fieldwork. Chapter 3 is a scholarly manuscript entitled *Shifting relationships: Key considerations in narrative inquiry*. In it, I focus on moral and ethical issues of engaging in narrative inquiry with Luanda. Chapter 4, 5, 6, and 7 are narrative accounts of Estero, Nelly, Atoti and Luanda respectively. Chapter 8 is the second manuscript: *Exploring the Meaning of Living with HIV as a Chronic Illness in Kenya: A Narrative Inquiry.* In it, utilizing Bury's concept of biographical disruption, I focus on Atoti's accounts of living with HIV as a chronic illness. Chapter 9 is the third scholarly manuscript entitled: *Involvement of People Living with HIV in a Kenyan AIDS Service Organization*. I discuss how the greater involvement of people living with HIV (GIPA) principles are appropriated in an AIDS Service Organization in western Kenya. In chapter 10, I discus the personal, social and practical implication of engaging in narrative inquiry with persons living with HIV.

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Chapter 2: Returning to Kenya

In this chapter, I describe my return to Kenya after 3 years of absence, to reconnect with the people and the place I had called home for 15 years. I describe the tensions I experienced navigating the strange but familiar socio-geographical landscape during this return. I briefly introduce each of the four participants whose narrative accounts follow in the subsequent four chapters.

It has been 10 years since my encounter with Solomon, a patient who, at that time, typified the HIV devastation in sub-Saharan Africa. But now, as I travelled back to Kenya to engage in a narrative inquiry with people living with HIV (PHAs), I was aware that the HIV landscape had drastically shifted since antiretroviral medications became the mainstay in HIV care. HIV morbidity and mortality had decreased remarkably as a result. Yet my passion to inquire into the lives of PHAs, however, remained undiminished. I longed to understand how PHAs composed their lives with HIV, now a chronic illness, and the challenges they faced. I was excited to return to Kenya to collect data for my doctoral research because it presented me with opportunities to reconnect with my home. I was going back to Ukweli, a city that I had lived in for about 15 years of my life. I too was returning to see my family, friends, colleagues, and acquaintances, and somehow reinforce those aspects of my identity that I perceived to have been eroded by my absence. Better still, it was a privilege for me to go back to explore the experiences of PHAs.

Leaving Canada for Kenya meant many things to me. This was the first time that I had left my family in a foreign country in order to return to Kenya. In my previous travels, I left my homeland and my family behind for ventures to worlds unknown, being certain that they had enough social support to draw on. In preparing to do my PhD field work, although I was certain that they would be alright without me, I wondered what this would mean to me and the work I would engage in. Moreover, after being acquainted with the lives of PHAs in Canada, I wondered how this would shape how I attend to the PHA's experiences in Kenya.

Boarding the airplane from Toronto to Amsterdam, at the beginning of a 40-hour journey to Ukweli, the preoccupation with how my family would cope in my absence clouded my thoughts. However, it was the Kenya Airways flight attendant's announcement in Kiswahili while boarding the plane in Amsterdam heading to Nairobi: *mabibi na mabwana, karibu katika ndeke la Kenya Airways nambari 789 kutoka Amsterdam kuelekea Nairobi* (Ladies and gentlemen, welcome to the Kenya Airways Flight 789 heading from Amsterdam to Nairobi) that awoke me to the reality that I was indeed going home. Although I had heard such announcements in Kiswahili many times before, this particular one sounded uniquely strange. Immediately, it transported me to places where Kiswahili is widely spoken and reminded me of the beauty and unity that it has brought to the 200 million people who speak it in the East African region. I also knew that Kiswahili would be a great asset to facilitate my engagement with those participants who might not speak English.

As I settled in my seat next to the window, I took note of the diverse nationalities of the people boarding the plane. I imagined some people were going home like me, while others were visiting or just transiting through. Soon an elderly couple sat next to me. Due to their age, they took a little longer than others to settle down. The elderly woman sat next to me and held a pamphlet entitled *Karibu*[12] *Kenya - Home of World Class Safaris.* I turned my attention to the

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[12] Karibu is a popular Kiswahili word for welcome.

paper she held and the meeting of our eyes signaled the beginning of a 10-minute conversation on diverse topics. From the conversation, I learned that the couple was from England and were on their 20th visit to Kenya. The love and allure of the Maasai Mara game reserve, Kenyan coastal beaches, and the Rift Valley sceneries repeatedly brought them back to Kenya, a place they called their second home. Their love for Kenya began in 1959 when they celebrated their wedding in a coastal resort. They had celebrated many more milestones on Kenyan soil since then. On this journey, they were celebrating their 54th wedding anniversary in a coastal city famous for its sprawling beaches. I learned that every so often the couple made a sojourn to Kenya to relive their past and refresh their memories.

As I told my story, I found myself struggling to explain why my research project mattered to others and me. However, it was the mention of the word HIV that rattled the elderly woman as though I had said something terrible. “You still have AIDS in Kenya?” she exclaimed rather shocked. “Every country has people living with HIV,” I explained trying to control my feelings. I could immediately read prejudice and disgust written all over her face. I wondered what the word HIV meant to her? The conversation did not go far and we immediately drifted to sleep.

As the plane landed at the local airport, I sensed the familiar smell of Kenya and beheld the beauty of the hilly mountain ranges covered with evergreen vegetation. The sights and sounds of Ukweli reminded me of how the city had, over time, shaped who I am. On my way out of the plane, I grabbed a local newspaper, and for once, I looked at it with a different appreciation. *The Daily Nation Newspaper* has been a media outlet that has communicated and preserved Kenyan spirit and identity for as long as I can remember. It is through *The Daily*

Nation Newspaper that Kenyans have composed and recomposed their identities as a nation and as a people since attaining independence from Britain. Its logo is embedded in my memory as an emblem of Kenyan identity, as I grew up seeing it, reading it, and feeling it.

Beating the chill and rain that dampened the otherwise quiet evening, I headed off to town where I spent the night and began to imagine how my life would unfold during the next couple of months during my stay in Kenya. A sense of strangeness, loneliness, and guilt engulfed me as I traversed through towns and suburbs along the way. Though these scenes were familiar, they seemed strange and nostalgic. I wondered if I was experiencing reverse culture shock or if I was too sensitive and cautious. However, the task ahead of me kept me focused, often wondering:

Who will you be?
Men or women, old or young?
Will I see Solomon?
Can I truly hang out with you?
How do you negotiate your identity?
Can I walk alongside you, as you live your HIV stories?
Will you be willing to talk openly about your life?
Will I hear you?
How do you deal with stigma and disclosure?
I wonder. ...

It did not take me long to reacquaint myself with the place and the people. After a day’s rest, I set out to sort out the ethics approval that I had applied for while I was still in Canada. It took about 2 weeks before it came through. I also learned that I needed additional clearances and approvals from Utumishi, an AIDS service organization (ASO) where my research was to be based. As I engaged with the official responsible for this clearance, I learned that Utumishi was formed in 2001 as a donor funded AIDS Service Organization (ASO), in response to a high HIV mortality rate in a government hospital in western Kenya. The ASO served about 140,000 PHAs through its antiretroviral program that had spread across 20 satellite clinics in western Kenya. Utumishi incorporated HIV research, care, prevention, and community service and offered diverse services such as HIV testing and counselling, access to antiretroviral medications, legal and financial assistance, palliative care, and nutritional programs.

Within Utumishi, I was introduced to John, a PHA and a community outreach worker who was to help me with the recruitment process. John, as I came to learn, was a poster boy for the Utumishi HIV program, having been among the first recipients of antiretroviral medications. Though he survived after developing AIDS[13], the impact of toxicity associated with the first generation antiretroviral medications left him almost blind; a constant reminder of this past. He had been impressed by my research, which he believed would enhance the visibility of the experiences of PHAs. John took it upon himself to spearhead the recruitment process, explaining the details of the research to potential participants. He took the contact details of those who expressed interest in being involved in the research. John and I met 2 days later when he handed me the contacts of the potential participants. Thereafter, I began to contact them individually using the cell phone numbers that John gave me.

Since all of the participants worked for Utumishi in different capacities, Utumishi premises became a place from which much of my research work happened. Whenever I had time, I went to Utumishi so that I could gain insights into the organizational structure and services offered by it. In so doing, I attended to the organizational narratives and every day

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[13] Acquired Immunodeficiency Syndrome is the final stage of HIV infection. People at this stage of HIV disease have badly damaged immune systems which put them at risk for opportunistic infections (OIs). http://aids.gov/hiv-aids-basics/hiv-aids-101/what-is-hiv-aids/

stories that service providers and patients composed together. Within a week after meeting John, I met Atoti, Estero, Nelly, and Luanda.

Meeting Atoti

Atoti, a 36-year-old woman, was diagnosed with HIV during a routine antenatal visit in 2000. At the time, she dismissed it as false positive. In 2004, pregnant for the second time, she retested positive for HIV. At that time, she decided to involve her husband Martin who, upon testing negative for HIV antibodies, immediately deserted her, remarried, and moved on with his life. Devastated and poor, she engaged in prostitution and sold illicit brew to support her family. By chance, Atoti met an HIV nurse who introduced her to an HIV support group. Through the support group, she was able to turn her life around. In 2006, Utumishi hired her as an HIV lay worker, a job that enabled her to rebuild her life. In 2009, her husband returned to her, dying of AIDS-defining illnesses. She nursed him to health and they added three more children to their family.

Meeting Estero

Estero is a 49-year-old man, whose first marriage ended in desertion, leaving him with two young children to look after. One month later, in a social event, he met and married Winnie, his second wife. The baby boy who was born to them died of pneumonia when he was 8 months old. In 2010, Winnie and Estero were diagnosed with HIV after Winnie was admitted to a hospital with advanced TB. Winnie died 2 months later. Coincidentally, Estero lost his job at the same time he was diagnosed with HIV. A job loss, an HIV diagnosis, and the death of his wife plunged Estero into an unprecedented psychological and socioeconomic crisis, the effects of which he continues to contend with. Three years after he was diagnosed with HIV, while attending an HIV clinic, he saw and applied for a position of a research assistant in an ARV stud, and was hired one year later.

Meeting Nelly.

Nelly, a mother of three, was diagnosed with HIV in 2002 when she was expecting her second child. She blamed her HIV infection on her husband's infidelity, which began soon after their first child was born. With a lack of social support to cope with her HIV diagnosis, coupled with a dysfunctional marriage, Nelly contemplated suicide. Later, she reached out to the Utumishi support group, which helped her accept her HIV status. Her association with Utumishi's support group led her to securing an employment as an HIV lay worker in 2006. Although Nelly later remarried, the trauma and scars of her HIV infection and a failed first marriage constantly haunted her.

Meeting Luanda.

Luanda was diagnosed with HIV after an abrupt illness, which was later diagnosed as meningitis. The doctor tested his HIV status without his knowledge and communicated the result in the presence of family and relatives. Unable to cope with the new diagnosis, he resorted to alcoholism and developed a resistance to antiretroviral medications. Luanda abandoned his job and relocated to his rural home, where he led a life of isolation. He turned his life around, after being warned that his liver was failing due to non-adherence to antiretroviral medications and alcohol use. He moved to Ukweli where he joined an HIV support group and in time, he stopped drinking alcohol and began to live positively with HIV. In 2009, he was hired by Utumishi as an HIV lay worker.

Negotiating purpose.

After negotiating consent with each participant, we agreed on possible meeting times, working around social, family, and work commitments of participants. During the first month of the research, I met participants at Utumishi for formal conversations during their free time. A tent standing outside the ASO became our meeting place of convenience. At the beginning of the conversation, I often led the inquiry, as I wanted to have deeper insight into their lives in a more structured way. Gradually, participants took charge of the relationship, signaling the shift in the comfort they felt relating with me. With time, they invited me to their homes to meet their family members. Participants also brought artifacts into the conversation that had significance in their lives. These included photos, newspaper cuttings, and academic certificates.

Formal conversations were recorded using a digital voice recorder and transcribed verbatim. Where applicable, Kiswahili translations to English were done at the time of transcription. Data editing was done to make the transcripts legible as the participants often spoke in grammatically incorrect English or juxtaposed colloquial phrases, native languages, and Kiswahili. Extensive field notes and personal reflections were written throughout the research time.

Interim texts emanating from the field text for each of the participants were written, informed by the field texts for each participant. These interim texts formed the narrative accounts for each of the four participants. Field notes, excerpts from the conversations, and personal reflections and my wonders about how the experiences of participants resonated with me, enriched the interim texts. Where applicable, a description of people and places was done to provide context of the places and people who were part of the study. Although all of the interim texts rendered themselves to a temporal representation, diverse starting points were identified as places where participants began to make sense of their experiences. For instance, for Nelly and Atoti, their childhood and youth narratives were their starting point in composing their HIV identity. For Luanda and Estero, failed marriages were their points of reference in which the location of their HIV identity and vulnerability was based.

Eight months after the end of my research engagement in the field, I returned to Kenya to negotiate the interim texts. Each participant agreed to meet for 1 hour each day to go through the interim text. Lunchtime within Utumishi premises was a convenient time for them for this purpose. I gave each participant a chance to read the text; Luanda struggled to read because of his sight problems, while Nelly and Atoti did not feel comfortable reading in English. Estero did not given a reason why he declined to read his interim text. After reading five pages, I paused to give each participant a chance to reflect on the text. Although I had told participants that they could stop me reading at any given time if needed (to address any issues in the text), they rarely used this privilege. It took us at least two sessions to read the interim text for each of the participants. At the end of this session, participants expressed their delight that I took time to develop a relationship with them in ways they had never experienced before. Furthermore, constructing their accounts that resonated with their realities of living with HIV was much appreciated. I thereafter made copies of each of the participants' final narrative accounts and gave this to them.

Conclusion

Returning to Kenya to engage with four participants over a 4-month period afforded me an opportunity to learn about current HIV discourses and issues at personal and national levels.

At a personal level, I was confronted with the daily struggles that PHAs faced in their endeavor to live with HIV. The intersection between poverty, stigma, HIV disclosure, and other psychosocial issues and how they shaped participants' HIV identities were forever before me as I related with the participants. At the national level, the nuanced social and cultural narratives of what HIV was and had become in an era where antiretroviral medications were available for HIV care, were evidenced through various mass media outlets and communal stories I was told whenever I shared my research interest. These further informed my understanding of the meaning that the participants derived in living with HIV. In the following chapter, I discuss the moral ethical issues of engaging in narrative inquiry with Luanda.

Chapter 3

Shifting relationships: Key considerations in narrative inquiry

Abstract

In this paper, I discuss the moral and ethical issues that arose while inquiring into the experiences of Luanda, a person living with HIV in Kenya. In particular, I attend to how my positioning in this narrative inquiry study evolved over time from an interrogator guided by a research puzzle to a listener and a narrative inquirer, who was guided by relational commitments. This shift demanded flexibility in my approach to the inquiry, to allow Luanda to take more responsibility for the inquiry and to develop my willingness and flexibility to *world travel* with Luanda to places that were socially significant to him. In so doing, the researcher-participant boundaries became blurred, calling forth ethical and moral wonders about narrative inquiry as a relational methodology. Travelling to Luanda's worlds also called forth deep and personal experiences, which allowed me to understand the geographic and social context of his life in new ways. The emergent personal narratives and a transformed researcher-participant relationship deepened my understanding of who Luanda was and called upon me to respond in relational ways, evoking ethical and moral tensions.

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This paper is situated in a larger project that involved inquiring into experiences of four participants living with HIV who worked as HIV lay workers at Utumishi, a Kenyan AIDS Service Organization (ASO). As HIV lay workers, they supported their peers who were clients at the ASO by delivering HIV education and providing moral support. Spending a considerable amount of time in their midst, as an observer, interrogator, socialite, and a friend, I observed them at work, held formal and informal conversations about their experiences, and visited with them in social places. In this manner, I gained a deeper understanding of the social, cultural, institutional, and medical narratives that shaped their experiences of living with HIV.

In this paper, I focus on the beginning of my inquiry into Luanda's experiences of living with HIV; guided by a research puzzle, I positioned myself as a researcher to elicit Luanda's experiences of living with HIV. Although this *formal* approach to the inquiry deepened my understanding of his HIV story, it failed to advance our relationship. Instead, his story of living with HIV obscured his deep personal and socioeconomic stories that became explicit only when I began to attend to his life in a different way. A shift in my attention to his personal and social life occurred when Lunda began to talk about his past marriages, which led me to spend more time with him outside of his work. In social places, he increasingly took more initiative and responsibility in the inquiry, exposing me to people and places of social significance to him. Subsequently, sensitive personal narratives emerged that helped me understand who Luanda was and how deeply his life was shaped by the socioeconomic difficulties he had experienced. These emerging narratives placed new challenges in our researcher-participant relationship and evoked ethical and moral tensions and complexities.

Turning to Luanda's Stories to Live By

When Luanda was admitted to the hospital with an acute illness, the attending physician tested for HIV antibodies without his consent. Afterward, the physician communicated Luanda's HIV diagnosis in the presence of family and relatives, leading to a major fallout between them. Unable to cope with his new diagnosis and the social consequences of his HIV diagnosis, Luanda turned to alcohol. This limited his ability to resume gainful employment and maintain his self-care. He relocated to his rural home, where he led a life of isolation and poverty and became an alcoholic. Due to his lifestyle, over time he became resistant to antiretroviral medications. He turned his life around when he was warned of impending liver failure. Luanda relocated to Ukweli and enrolled in an HIV support group at Utumishi. There he found support to make a positive lifestyle change and was able to adhere to antiretroviral treatment. In 2009, Luanda was hired by the ASO as an HIV lay worker. He had demonstrated a transformation in his personal lifestyle, a mastery of HIV knowledge, and a willingness to live and tell his HIV story publicly in his role as a lay worker.

Luanda derived immense pleasure talking about his HIV experiences, which he believed provided an opportunity to support others at Utumishi and in the community. Particularly, he gave HIV talks in churches, community colleges, and schools in Ukweli city. His personal experiences were central to the telling of his HIV story. This was his way of giving back to the community and honoring the support he had received from Utumishi; in his eyes, this had saved his life. The hardships and fallouts that accompanied his HIV diagnosis made Luanda amiable, understanding, and accommodative to others who were living with HIV. Spending time with Luanda in his office at Utumishi, I witnessed his intensity, devotion, and commitment to HIV education and care. He used his HIV experiences to educate and encourage HIV clients to receive care at Utumishi. In the many conversations we had, I heard many versions of his HIV stories, flawlessly told in a “matter of fact” tone. I wondered if he had come to perfect these stories due to his numerous tellings. I often wondered if he felt bothered by HIV stigma.

Narrative Inquiry

Narrative inquiry, a study of experiences told in and through storied form, helped me to make sense of Luanda’s experiences of living with HIV. Through listening, observing, living alongside, writing, and inquiring into the texts (Clandinin, 2006), I gained insights into his experiences. Through sharing stories, the details of life experiences, including people’s pain, hopes, beliefs and dreams, can be understood (Bell, 2002; Coles, 1989). This understanding is situated within place, across time, and in social contexts (Clandinin & Connelly, 2000). Narrative inquiry draws its philosophical roots from Dewey’s theory of experience (1938) which posits that every experience reflects a continuous and interactive process, and is constituted by interaction between subjects and objects, between self and the world. Narrative inquiry is grounded in experience, a foundational ontological category for pragmatists, from which all inquiry proceeds and which is considered the essence of being and a source of knowing (Barrett & Stauffer, 2012; Clandinin & Rosiek, 2007). Epistemologically, narrative inquiry rests on the assumption that human beings make sense of their experiences by attending to those elements of the experiences, and interpreting them based on the societal stories available to them (Barrett & Stauffer, 2012; Bell, 2002; Stalker, 2009).

As a relational methodology, relational ethics guided my inquiry into the experiences of Luanda as a person living with HIV. Ethical issues are continuously present throughout narrative inquiry, as relationships between the researcher and the participants continuously unfold, take turns, and transform (Clandinin & Connelly, 2004; Josselson, 2007). Relational ethics commit the researcher to act from his "heart and mind," and to engage in continuous self-reflection as a way to own up to the research process and its consequences (Ellis, 2007). The principles of relational ethics acknowledge, recognize, and value mutual respect, dignity, and connectedness between the participants and the researcher. It also prescribes the attitude and practice of the researcher toward the participants (Ellis, 2007). This deep respect promotes authentic connections, allowing for collaboration and co-creation of knowledge between participant and researcher (Dillon, 1992). It also demands the creation of moral spaces where respect for the participants and their experiences is nurtured (Bergum, 2004).

Living in the Midst

> As researchers, we come to each new inquiry field living our stories. Our participants also enter the inquiry field in the midst of living their own stories. Their lives do not begin the day we arrive, nor do they end when we leave. (Clandinin & Connelly, 2000, pp. 63–64).

As I began to inquire into Luanda's experiences of living with HIV, I remembered experiences that were embedded in time, when, as a Registered Nurse in a medical unit, I met and cared for dying HIV patients. At the time, antiretroviral medications were not available and the memories of being a helpless witness to the death of patients under my care stayed with me. I shared in the agony and trauma of caring for patients and interacting with loved ones; some oblivious to the cause and fate of the illness that had befallen them. Solomon was a middle-aged man and one of the HIV patients whom I cared for when I worked as a Registered Nurse in a Kenyan hospital. I still remember him clearly. He stood out to me as an iconic representation of the HIV devastation in Kenya. With a stable job, an adoring wife, and beautiful young children, Solomon had what many may call a happy, successful, and fulfilling life. Knowing that he had only a couple of months to live, he asked us to conceal his HIV diagnosis and prognosis from his family. Although this request appeared unethical, given that there were other people involved in the relationship with him, we felt bound by his need for confidentiality. While initially admitted to the hospital with pneumonia, Solomon's health drastically and rapidly deteriorated. He developed full-blown AIDS, became demented, and lost cognitive and motor functions.

Due to the intrigues and paradoxes relating to Solomon, he became a patient that I really wanted to know. He was evidently affluent, highly educated, influential, and successful professionally, an exact opposite of how the people dying of HIV were depicted in the media. Yet, there were many things that did not add up in his life. Why was he seeking care in a government facility that was resource poor, far from home, and in a workplace town when he could afford high-end care in a private hospital? What was it that attracted visitors to him? What did he think society thought of his illness? Why could he not share the diagnosis with his wife? I wondered about these inconsistencies. Since my experiences with Solomon 10 years earlier, I believed that the HIV landscape had significantly changed. For example, antiretroviral medications that were unavailable 10 years earlier were now the mainstay in HIV care. I often wondered how different the experiences of Luanda were compared to those of Solomon.

At the beginning of my research relationship with Luanda, we met at his workplace for formal conversations, each lasting about 45 to 60 minutes. Often these conversations were interrupted by clients seeking interventions or callers who called him on his cell phone to consult him on diverse issues. Although he continuously assured me of his interest in participating in this study, I remained apprehensive, lest I appear intrusive and insensitive. Furthermore, due to our significant age difference, I feared that Luanda might not be comfortable sharing intimate details of his life with me. I also feared that since I was HIV negative, I might not comprehend the thrust and gist of the stories he would live and tell. Yet, the pressure to understand Luanda's experiences of living with HIV well was always present.

To address my uncertainties, I "directed" the conversations, carefully negotiating the questions I asked, in order to elicit the details of his experiences living with HIV. I invited Luanda to tell me how he came to know his HIV status and how it had shaped who he was becoming. A general question, such as: *"Could you please tell me how you came to know your HIV status?"* set the stage for meaningful conversations that uncovered his experiences before HIV diagnosis, the diagnosis experiences, and life after the diagnosis. We kept returning to these stories during the 3 months that we were engaged. In so doing, I was filled with details of how these experiences had shaped his identity as someone living with HIV.

Luanda came across as easy to engage and generous with information, often times giving more information than was asked. I wondered if it was his way of calming my visible uneasiness of being in the midst of his HIV stories. Although he did not have any visible HIV signs or symptoms, he made his HIV stories believable by recounting them chronologically and in a convincing tone. Emotional scars that became obvious in his telling somehow sustained his HIV identity. His experiences with alcohol and his non-adherence to antiretroviral medications also formed vital aspects of his telling.

In our formal meetings together, Luanda wanted only to talk about his experiences of living with HIV, the role of Utumishi in rehabilitating him, and the many clients he served. I somehow sensed that his responses to my inquiry were well choreographed to what he imagined I wanted to hear. Over time, I increasingly wondered what our relationship would look like outside of Utumishi. How would he story himself outside of Utumishi? Even with the many meetings we held, I felt as if our relationship was not progressing "naturally." I felt that although I knew a lot about Luanda's experiences living with HIV, I did not yet know who he was. At some point, I reached out to my academic response community (supervisory committee members), out of frustration that I was not experiencing a "breakthrough" with Luanda in the way we engaged. Although they urged me to be patient, I kept wondering what I needed to do to engage with him in a relational way.

> *I have seen Luanda several times and although I feel I have come to deeply know his HIV story, I still feel like a stranger to him. I wonder if he too sees me as a stranger. I do not know who he is outside Utumishi and how he lives his life outside of the ASO. Who is he in the community, or as a father and a husband? Why is he not interested in inquiring about my life? I feel like I need to connect with him in a different way, but I am not sure how. Maybe I need to attend to his social life. But how do I engage him in the telling and living of his social stories? How do we begin? How do I know which stories are important in his life? I feel I need to change my questions and approach towards him, but I do not know how. (Field notes).*

Looking back now, although I was anxious at how slowly my relationship with Luanda unfolded, engaging Luanda in formal conversations brought out significant events in his life from his context and perspective. Alongside him, I was able to imagine his life as he told and retold his experiences. In so doing, I entered an emotional landscape (Magowan & Wrazen, 2013) with him and grasped some of the vividness of his life. Subsequently, one story led to another (Campbell, 2011), allowing for a renegotiation and connection to other stories that he lived and told.

A major turning point in our relationship came during an intriguing marital story that he told, a major departure from the HIV stories I had been listening to and observing. When Luanda told me that he had been married four times, I knew that for the first time I had a chance to inquire into his social life. This story became an entry point. Although Luanda did not have a problem explaining how each marriage began and ended, the genesis and process of his fourth marriage rattled my comfort:

> *I met my current wife when I was working at the HIV clinic at Utumishi. My initial impression when I met her was that she was sociable. She told me she was a university graduate, although I later learned that it was not correct, as she was a form two (Grade 10) dropout. I came to learn most of the details of her life after we had advanced in our relationship. There were other inconsistencies in her life that I figured out after doing many investigations. She told me many lies about her life, and I unraveled them with time as we continued to live together. For instance, she had lied to me about her real name, tribe, and where she comes from. I bumped into some of her legal documents and photocopied them without her knowledge. I was not deterred by these inconsistencies, as I was more curious to know who she was. I had thought that she was hesitant to disclose her true self because we were strangers, but now that we were getting serious in our relationship, I expected things to change. I was also beginning to be actively involved in her wellbeing. The more I tried to get involved in her life, the more I bumped into more inconsistencies and she was increasingly becoming uncooperative. (Luanda)*

Luanda was volunteering at an HIV clinic when he met Anita, who had come to the clinic as a walk-in patient. Luanda could not recall what attracted him to Anita or the initial circumstances that led him to invite her for lunch. He does remember that she gladly accepted his offer for lunch after her clinical appointment was done. This casual invitation extended to his house to “see where he lived,” which became the genesis of their 2½-year marriage. Without knowing one another and with HIV as their only common denominator, using both conventional and non-conventional ways, Luanda embarked on a journey to know who Anita was. In this telling, he was visibly frustrated by the complexities in this marriage to Anita. I was uncomfortable to attend to the telling of his relationship with his spouse in this manner. The use of negative descriptors to illustrate his relationship with his wife and his perception towards her made me wonder what was appropriate to be told to a researcher. Although I was uneasy with the way he storied his wife, I imagined that he must have told it for a purpose. However, I wondered if I was able to question the stories offered to me. Would he be offended if I raised my reservations about them? I too wondered: where did my discomfort come from?

Despite this discomfort, Luanda's telling about his social life further tweaked my interest to get to know him in his social milieu. I toyed with the idea of making a home visit to reconcile some of the stories he told me or perhaps to learn who Luanda was. When I asked Luanda about the possibility of visiting him at home, he did not raise any objections, yet he too was not overly enthusiastic about the idea. I wondered if the ambivalence towards my proposal meant that he was uneasy with the possibility of a home visit. He nonetheless gave me a date and a time to visit, certain that both he and his wife would be available. Even with the offer to visit with his family, I was still hesitant. I felt as though Luanda had compromised my judgment regarding his wife. What was I to think of her when I finally met her? Would it even matter how I perceived her since she was not my participant? Why was I affected by what Luanda had told me about his wife? I had many questions.

As I considered the impact of the stories he told me, I felt as though I was experiencing moral tensions – moral because I had to endure a telling that challenged my values about how I thought partners ought to be storied. I wondered if there were ways to protect myself from stories that influenced me in ways I did not want. I wondered if my relational responsibilities extended beyond Luanda to his spouse.

Shifting Stories of the Midst

Luanda and I agreed that I would visit his home on a particular Saturday morning. On the day of the visit, I found Luanda waiting for me at a place we had earlier agreed, holding baby Anabel against his chest. He led me uphill, towards his home, which was about 100 meters away. His home was a freshly built semi-permanent house that sat on one eighth of an acre of land. This had been Luanda's home for 2 months and since the construction was ongoing, we set ourselves outside the house on plastic chairs under a scorching sun. His home was in a rural setting, where the community shared resources such as a village well, and grazing space. While I was there, Anita was laundering clothes near the village well and we did not interrupt her work.

The stories that Luanda had told me about his relationship with his wife were still on my mind. I hoped by meeting at his home, he would share different stories compared to those he shared at his office. In his home, we briefly talked about contemporary local and national politics before Luanda shifted to talk about his experiences since he relocated to his new home. I learned that he had secured a loan to buy property and develop it, a move that had strained his finances to such a degree that he was unable to afford basic necessities such as food and bus fare to work:

> *Every day, I wake up at 06:00 a.m. and by 06:30 a.m. I leave the house without taking breakfast to begin 1½ hour, 5 kilometers' walk to my office at Utumishi, as I cannot afford bus fare. By the time I get to the office, I am very exhausted and hungry yet I am expected to be engaged with the HIV clients.*

I was troubled to learn that Luanda walked for 5 kilometers to and from work daily because he was unable to afford bus fare. As the details of his socioeconomic status unfolded, I recalled that in our previous conversations I did not suspect that he was someone who was struggling financially. This was a remarkable departure from the HIV stories he lived and told. I wondered if he would have told these stories if we had we continued to meet at his office. As I imagined how he was trekking to and from work, I considered how hard this must be, particularly during the rainy season when the rivers flood and the paths are slippery and impassable. This realization helped me to understand the effort and determination he demonstrated to fulfill his duties at Utumishi.

In an unprecedented move, he brought out his current paystub. His paystub showed that although his gross monthly salary was 26,000 Kenya Shillings (KShs) (CAD 330), his net income was only 8,000 KShs. This was inadequate to support a family of three. Two thirds of Luanda's gross salary went to deductions: long-term loan, emergency loan, shares to a co-operative union, income tax, and repaying advances on his salary. The net salary was clearly insufficient to sustain his family. In my conversations with Luanda, I realized that living from paycheck to paycheck or on credit meant that he rarely took breakfast, and often times he skipped lunch. Each month he had a carryover debt that he had to pay with his subsequent salary. Further, Anita was unemployed and was expecting their second baby. This meant that Luanda would face even more demands on his already inadequate income.

Even so, I did not understand why he suddenly shared stories of his financial strain with me; it took Luanda only a very short time to disclose a lot of information about his financial situation. In this telling, I did not feel he was attempting to impress me, as I felt he had done in telling his HIV stories. Although I was shocked at the scale of the disclosure, I became even more impressed by his perseverance to maintain employment at Utumishi. I only managed to nod in acknowledgment to his stories, not knowing how else to respond to them. In the home visit, Luanda did most of the talking and I listened. I needed to understand, from his perspective, which stories he considered important to live and tell without being prompted or directed by me. To my surprise, socioeconomic stories dominated our conversations during this meeting, and he did not make any reference to his HIV stories. This was a huge departure from the stories I had previously learned about.

Our visit lasted slightly over 2 hours and since Luanda had a speaking engagement in town, we had to cut our conversation short. On our way out, I asked him if we could walk together for some distance, using the paths he takes to work and back. We followed a narrow path that meandered through plantations and bushes, rugged terrain and slippery slopes. It took us about 1 hour to reach the motorable section of the road. The hot sun unrelenting, we were exhausted and dehydrated from the 1-hour walk; we then boarded a taxi for the rest of the journey. I was glad that I had a chance to participant in what had become Luanda's daily labor of love. Furthermore, walking alongside each other helped us bond in our research relationship.

The home visit that I had hesitated to undertake somehow became a catalyst for our relationship. Although I never had a chance to speak to Anita, visiting the geographical space Luanda called home was significant to our relationship. It created a space where I was able to come to know Luanda socially. Walking together allowed us to share experiences, which in turn helped me to attend to his stories differently. I felt I was beginning to understand Luanda better, having explored his experiences living with HIV and his social world. Luanda, too, began to show interest in my life and my family as we walked together, something that I felt had not happened in our previous conversations.

As we parted, we agreed to meet at a social place for another conversation. By shifting our social space, I hoped that I would continue to be able to attend to his stories differently.

Several days after my visit to Luanda's house, we met at a restaurant that was familiar to both of us. While I took it as a conversation over an ordinary lunch, Luanda looked at it with a different appreciation. I learned that he had not dined at a restaurant for a long time due to the economic strain he faced. As we began to eat, his countenance changed. Suddenly, he appeared unhappy, unsettled, and disturbed, becoming a different Luanda from the one I had come to know. He told me that he was distressed by his inability to provide for his family. He was particularly heartbroken that he had to turn down his daughter's daily request to buy beef for dinner.

I wondered what prompted Luanda to open up in this way. Did our meeting place prompt him to tell these stories? Realizing that I had spent on lunch, an amount sufficient to buy his weekly groceries, I began to question the morality of inviting him for lunch in the first place. Should I not have given him the money to assist with some of his financial needs, rather than lavish him on a lunch beyond his means? Yet, if I did not invite him for lunch, how and where would he have told these stories? I wondered about my moral and ethical obligations towards Luanda in that moment. I did not imagine that his sharing would challenge the researcher-participant relationship, our relationship, in the way it did. I really wanted to somehow respond to his concerns. If I had given him money to sort out his financial situation, how would it affect our research relationship? Was it enough just to know that he lacked basic needs such as food? I had many questions. The more Luanda shared about his situation, the more I realized how ill equipped I was to attend to the social concerns that he presented to me. If I remained ambivalent to his issues, how would it affect our research relationship?

Unlike the previous conversations about HIV stories, Luanda was direct in his telling of the socioeconomic hardships he faced. His signature smiles, which were associated with his HIV narratives, were few and far between when he talked about his socioeconomic difficulties. At some point, I wondered if I was beginning to see the real Luanda. Was he wearing a façade all along when he lived and told HIV narratives? What about the sentimental stories of his relationship with Utumishi? What was the intersection between his experiences of living with HIV and his socioeconomic hardships?

Relational Collaboration in Narrative Inquiry

At our second lunch conversation outside of Utumishi, I let Luanda decide on a venue where we would meet, with the condition that it should be quiet and appropriate for a confidential conversation. He took me to a newly renovated butchery, filled with smoke and drenched with the aroma of all kinds of cooked meat. We joined a long queue of customers, each patiently waiting for their turn to find a spot in the packed eatery. At the restaurant, waiters in blood stained coats ran back and forth to attend to clients, customers called for attention, and others just made a nuisance of themselves. I still remember the noise and chaos of the eatery. In my mind, the sheer noise and disorder at the eatery was sufficient to seek an alternative eating-place. Furthermore, I did not know how long it would take us to be seated. However, from the look on Luanda's face, he was undeterred by the wait, seemingly determined to eat at the restaurant. We waited patiently for about 15 minutes before a table for two was vacated and we could settle for lunch. I wondered if Luanda understood my request for a quiet place to meet. Did it matter to him in that moment?

At this point, I was not overly concerned about the need to have *control* over the way our relationship unfolded. Instead, I let Luanda share the responsibility of directing our relationship in the way he deemed fit. After all, he was the focus of the conversation and his concerns were central to our inquiry together. I no longer wanted to be presumptive about what I thought was a meaningful engagement from Luanda's perspective. I hoped that my actions towards him demonstrated the value I placed on the relationship with him and the respect I had towards him. I wanted our relationship to flourish.

Luanda added more layers about his socioeconomic struggles at this meeting. Although I had resisted attempts to become emotionally involved in his telling, it was difficult in the face of the hardships he shared. The more he shared about his personal experiences, the more I found myself empathizing with him, unable to completely detach myself from the feelings I had for his predicament. I found myself imagining what it would mean if I was the one unable to provide the necessities of life to my children. I too imagined how this financial situation had undermined his sense of manhood, esteem, and ego. By thinking in this manner, I knew I had significantly shifted in my approach towards Luanda; I had transformed from a detached researcher who was solely preoccupied in pursuing a particular story, to an empathetic collaborator. Although I struggled to attend to what Luanda was saying because of the noise that surrounded us, I was glad that we spent time at the place of his liking. There were many moments of silence in this conversation between Luanda and me. I wondered what to tell him when he bombarded me with his needs and anxieties. Was silence a possible way for me to respond? I did not know what to do.

> *After this lunch meeting, I felt as though I was in an emotionally mixed situation because when Luanda shared his financial and social problems with me, I did not know how to respond. Do I give him money? Am I allowed to empathize? Does he see me as someone with some privileges and access to money that can help? And if so, how do I present myself in such a way that I retain my research identity? How could I not respond when his needs are legitimate? What responsibility do I have towards my participant that allows me to decide what I can give to them? How do I maintain a meaningful*

> *engagement with him that is purely academic and not social? How do I hear his problems? (Field notes, 2013)*

The Relational Transformation

At the beginning of the study, I endeavored to maintain a researcher identity, carefully following the research puzzle to inquire into Luanda's experiences of living with HIV. However, this approach did not support the relationship I had imagined we would form. Instead, it somehow encouraged Luanda to tailor-make responses according to what he thought I needed to hear. A major turning point in my relationship with Luanda happened when I began to inquire into his social life, by disrupting my own sense of comfort and safety to visit with him in social places, to understand who he was outside Utumishi. In so doing, we created an environment that supported the emergence of new possibilities for him to live different stories.

Lugones' (1987) idea of *world travelling* resonated with me as I thought about how my relationship with Luanda had shifted; it shifted because Luanda and I had reoriented our inquiry in social spaces that mattered. At the onset of the relationship I felt as though I perceived him *arrogantly* by guiding the research conversations in a way that was borne from my imagination about what mattered in the lives of people I had come to meet. The necessity to *world travel* with Luanda to his social worlds and become *at ease* in his worlds transformed me from an *arrogant perceiver* to an empathetic collaborator who identified with him. By travelling to his worlds, I understood "what it is to be *him* and what it is to be myself in *his* eyes" (Lugones, 1987, p. 17) (emphasis mine). This created a shift in the stories he told me and challenged my assumptions about which stories and worlds were of significance to him. I, in turn, subjected myself to his scrutiny allowing collaboration and co-creation of our experiences together. Developing a nonhierarchical relationship based on mutuality and reciprocity (Carter, 2008; Josselson, 2007) demanded humility, honesty, and respect on my part. In the end, I embraced Bochner's (2002) thoughts that

> Narrative inquiry dissolves traditional boundaries between the researcher and the subject. As a researcher, our lives and our experiences significantly influence what we project onto the people and events we study. The people and the events we study, act back reflexively on who we become and what we do. (p. 77)

The relational transformation I experienced blurred the researcher-participant boundary causing me to be more accommodating, flexible, and adaptable to the dynamics in the relationships with Luanda. I revised my research plans, shifted expectations, and explored new ground in order to support and strengthen the relationship with Luanda. In the end, we created possibilities of living and telling personal stories in diverse ways. I concur with Lieblich (1996) who noted that "sympathy and flexibility pays when people find a sincere listener, they profit from sharing their experiences even if they are painful" (p. 177). I also got involved in Luanda's life in ways I had not imagined. For instance, in buying Luanda meat to share with his family, I acted upon the moral responsibility I felt toward Luanda; to temporarily relieve him of the tension he was experiencing from his inability to provide for his daughter. I concur with Widdershoven and Smit (1996) who posited that by attending to the stories as told, and by understanding the situation and people involved, one can make ethical decisions on what is the right thing to do when confronted with a difficult moment.

The Moral Ethical Tensions

In pursuit of research puzzles, purposes, transitions, and intentions are continuously negotiated as both the researcher and the participant get to know each other (Clandinin & Caine, 2013). Clandinin and Caine (2013) remind us that while the intention is to enter a relationship as a researcher, the participant sees the researcher as one in a relationship. Yet, the tension of not wanting to offend Luanda by asking sensitive questions was always present. Miller (1996) noted that the fear of asking hard questions about the narrator's personal life comes from the possibility that the narrator will resist or feel uncomfortable, a disposition that may hamper relationship development with a participant. Furthermore, my inability to influence how stories are lived and told (Lieblich, 1996), meant that I was flooded with details, not only of his life, but of significant others that I found difficult to hear. How to live with the consequences of what I heard was an ongoing concern (Bar-On, 1996).

Even though I started as a researcher, I soon realised that a trade-off between the need to maintain a healthy research relationship and the need to have the participant engage in the relationship was necessary. In Luanda's case this engagement was critical to the relationship. Opting not to "turn away from the participants' needs and wishes" (Clandinin & Caine, 2013, p. 170), but to do whatever was needed to make the relationship work, meant that I spent time with Luanda at his home and in social places in his community. By opening myself up in this way, moral-ethical uncertainties arose from the stories Luanda began to live and tell. Brinkmann and Kvale (2008) noted that in conducting qualitative research, a researcher may be confronted with uncertainties which are complex and unpredictable and which raise questions about whether or not a researcher should respond to sensitive stories. Responding or not responding both have ethical implications.

In my research engagement with Luanda, the explicit and procedural aspects of ethical consideration were straightforward to execute, as they were clearly spelled out by the Research Ethics Board. However, relational ethics, which are at the heart of narrative inquiry, were difficult to negotiate or foresee and remained a challenge as the research unfolded (Ellis, 2007; Josselson, 2007). At the start of the study, I imagined that my ethical commitment only went as far as protecting my participants from harm or injury. I never imagined that I would be significantly affected by the stories I came to hear. While I agree with Josselson (2007) that the greater the rapport with the participant, the deeper the findings that come out of the inquiry, I also recognised that I inadvertently partook and shared in Luanda's vulnerability and became what Behar (1996) referred to a vulnerable observer.

Ontological Commitment

Caine, Estefan, and Clandinin (2013) contend that narrative inquiry is a negotiated research practice whose ontology proceeds the emergence of a research puzzle calling forth obligations and commitments. To these authors, the first responsibility for a narrative inquirer is to the participant (Caine et al., 2013), which connects the lives of the researcher and the participant in a way that allows mutuality, respect, and ethical engagement to occur. Relational commitment to research recognizes the centrality of the experience, a fundamental ontological category from which all inquiry proceeds (Clandinin & Rosiek, 2007).

My relational commitment to Luanda meant that although his medical, social, and economical vulnerability emerged as our relationship grew, I needed to attend to those vulnerabilities. It demanded that I carefully negotiate my relationship with him and, with flexibility, strike a balance between my needs as a researcher and his as a participant. In the end, commitment and diligence to understand his storied life and respect the life he lived took precedence over my own needs as a researcher. My own sense of comfort became secondary in light of the stories he lived and told. This required that I inhabit new and unanticipated places and spaces. I was rewarded by an evolution in our relationship, which called forth different stories and allowed me to understand his experiences in new ways.

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Chapter 4: Narrative Account for Estero

After giving me contacts of potential participants for my research, John directed me to Estero's workstation, a couple of meters across from his office. Without alerting him, I decided to see if Estero was in his office. As I walked towards his office, it dawned on me that I was beginning a journey where I would walk alongside participants and attend to potentially sensitive stories of their lives. Although John had assured me of participants' enthusiasm and willingness to participate in this study, I still wondered how this eagerness would translate into a relational inquiry. Furthermore, I did not know if this enthusiasm would be sustained over the period I would be inquiring into their lives. After walking a couple of minutes, I located the office door with a plaque that read *ARV Study,* on it. At the entrance of the office, I met a middle-aged man who was serving tea. Asking him for directions to Estero's workstation, he pointed three rows ahead and simultaneously, Estero stood up and we exchanged greetings. He pulled up a chair for me to sit and we formally introduced ourselves. Estero ordered a cup of tea for me as he concluded some paperwork.

Estero's office was situated in what was originally a long veranda that had been partitioned into small cubicles serving as workstations for the researchers in the program. These workstations were just big enough to fit a chair and a desk. To maximize the office space, overhead shelves for storing stationery and other materials were installed on the cubicle walls. Given the human traffic to his office and the constrained space, I could see that Estero went out of his way to make me feel comfortable. Estero then moved his chair in my direction and I simultaneously handed him my research documents to read. He nodded in agreement to all the things I told him about the project. My initial impressions of him were that he was an agreeable and a polite person. I later learned that John had briefed him regarding my project. Although he was willingly recruited to the study, the fact that he did not ask me any questions or make any objection regarding the demands and commitments of the research project made me wonder if he fully understood his role in the research. He nonetheless assured me that he would participate in the study wholeheartedly. I took him at his word, wondering what I would need to do to sustain the enthusiasm that he expressed in this meeting.

It was Estero's turn to explain to me his work at the agency. I hoped to have a sense of the work he did and how it related to the greater Utumishi mandate. Estero told me that he worked as a research assistant in a study that monitored the side effects of antiretroviral medications among first time users. Any HIV client presenting with a rash, itching, and diarrhea[14] was referred to Estero's office for enrollment and follow-up. While he was still explaining his work, a client stopped by, holding a small yellow card. I excused myself so that the client's confidentiality would not be compromised. From time to time, clients continued to present themselves to Estero during our visit, interrupting our conversations.

My overall impression was that Estero had a busy role that required him not only to enroll clients into the project, but also to share his experiences of living with HIV for education and support purposes. Since any conversation could be overheard by virtually anyone in the workstation, I wondered how confidentiality was maintained between clients and staff. As we came to the end of our first meeting, Estero indicated that he was available to meet me on selected evenings when he had no program going on in his local church. To him, missing a

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[14] Diarrhoea, rash, and itching are common adverse effects of antiretroviral medications. These symptoms indicate how well a client is tolerating medications.

church program was not an option. Given the importance he attached to the church program, I wondered what role it played in his life.

Four days later, Estero and I met in a café located in the middle of Ukweli city, a quiet and ambient place that was ideal for a confidential conversation. Although I would have preferred to have met him again at his work place, in order to have insights into how the collegial and institutional narratives shaped his work and HIV identities, I realized his workspace was not suited to hold confidential conversations. Estero arrived 10 minutes after me with a backpack dangling over his left shoulder. I had intentionally sat in an open space facing the entrance of the hotel. That way, it was easy for him to spot me.

As we settled for tea, I noticed Estero gazing at the setting sun as though he was in a deep contemplation. I wondered what he was thinking about. Was he worried about something? Estero later told me that it had been a long time since he ate out in a restaurant due to his financial situation. Instead, he preferred to spend his free time either in church or at home. Although I was curious to know what he meant by a "financial situation," I was mindful of the prevailing socioeconomic hardships in Kenya. I nonetheless hoped to understand this as our relationship unfolded. Halfway through our conversation, I learned that we had a couple of convergent interests. For instance, just like me, Estero was an Arsenal Soccer Club[15] fan and an evangelical Christian.

Estero was curious to know how I ended up in Canada. Beginning from my relocation to Ukweli as a high school graduate, to attending university and my back and forth movements for

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[15] Arsenal Football Club is one of the leading soccer clubs in England. In Kenya, many youth and middle aged men are ardent followers of the European and English Premier Soccer Leagues.

job and study purposes, I explained to Estero how my 15 years of living in Ukweli had shaped me. Being mindful that the conversation was not about me at that moment, I tried to steer the conversation towards him. Even then, I was still hesitant to engage him directly about his personal experiences of living with HIV. However, I drew comfort in knowing that Estero knew precisely why he enlisted in this study. Moreover, he knew that he had an option to not answer any particular questions in accordance with ethical stipulations of the research.

To break the silence, I asked him: *"Could you please tell me how you came to know your HIV status?"* Putting his cup down, Estero looked up, gazed straight at me, and then cleared his throat, as though in preparation for a big announcement. I wondered if he was taken aback by this question or if that was his way of responding. In retrospect, I now wonder how appropriate it was to approach our first conversation in that way.

> *I will start my story from the beginning. My [first] wife and I got our two children in 1990 and 1996 respectively. In 2007, for some reason, our relationship deteriorated drastically and irreparably and resulted in separation. She left me with children and went to live in Europe, where she is since. I decided to move on with my life, as I needed someone to help me raise my two children. Soon I married Winnie, a single mother of one.*

In the first 3 minutes of our conversation, Estero seemed to have summarized his life experiences. I was curious to know why he opted to start from the "beginning" when I asked him to narrate to me how he came to know his HIV status. What was this "beginning"? Was it a point in which his realization of life's connection with HIV began, or was it a way he chose to understand himself as a person living with HIV? Did he want me to understand the bigger picture of his life's circumstances, rather than focusing merely on his HIV diagnosis? I wondered.

During our first meeting, Estero skimmed through the details of the circumstances that led to the breakdown of his first marriage. It was evident that a mere mention of his first marriage evoked raw emotions that made his countenance change from a jovial and upbeat man to a cold, emotionless one. Seeing his countenance change in this manner suggested a sadness of heart and, as such, I refrained from probing into the marriage issue at that time. Instead, I let Estero focus on Winnie, his second wife, who he was immensely delighted to talk about. Even then, I wondered if the first wife's desertion was connected in any way to his HIV story.

Estero's story of being deserted by his first wife sounded peculiar at first. To my recollection, in a Kenyan society, it is men who often abandon their families, walking away to start other families, due to the influences of substances such as alcohol and drugs. Since the converse was uncommon, as Estero told this story, I wondered what motivated such a fallout. This desertion must have heavily impacted his ability to discharge his parental duties, or so I thought. I wondered if he felt equipped to look after the children's needs on his own. Did he have the skills or tenacity to look after them by himself?

It took Estero a couple of conversations to finally open up regarding the circumstances that led to his wife deserting him. During our first conversation, a major disagreement was the only reason he gave as the genesis of this disintegration. In one of our informal lunch conversations, without any probing, he revisited the issue of his first marriage:

> *Let me tell you something about my first wife. Before she deserted me completely, she had left for overseas without telling me for about 3 months. Her boss, who was a friend, often asked me where my wife was and I had no answer. Her phone was switched off and her sister was the only contact person I had. Whenever I enquired about her, she would dismiss me "leave her alone. If she were dead, I would tell you. Stop bothering me." This alerted me to a possibility that my wife could be having an affair with someone. When she came back, she never explained to me satisfactorily where she was and then, all of a*

> *sudden, she became cold and our relationship deteriorated. Without my knowledge, she was making plans to go. That was the major disagreement I told you about.*

From this conversation, it became apparent that the desertion by his wife was a culmination of a difficult marriage situation, which had greatly undermined his manhood and bruised his ego. This was a very painful experience for Estero to relive. Witnessing him agonize about how he was despised by his in-laws due to his humble socioeconomic status, I somehow appreciated his sense of helplessness in holding his family together under such circumstances. His inability to prevent his wife from disappearing from his home is a testimony to this helplessness. This was uncharacteristic for a man of a Luhya[16] tribe that is known for its patriarchy and use of gender-based violence as an instrument for enforcing wife submission. Estero later told me that the trauma of family breakdown and desertion was so immense that he remarried in haste. The urge to marry was so strong that he did not have time to fulfill customary practices such as paying dowry or taking precautionary measures such as doing an HIV test. Understandably, he needed someone to help him raise his young children.

> *When my first wife deserted me, I experienced an indescribable pain. I felt very vulnerable and I began drinking heavily. My children were left when they were young and I felt I needed someone to help me with their care. I was so desperate for a wife that anyone who would come my way, I was ready to marry. It took me about 4-6 months after my first wife deserted me to start seeing someone who I would later come to marry as my second wife.*

Thinking about how quickly he remarried, I wondered about the pressure he must have been under to find a partner. Did the children pressure him to get them someone to call “mama”,

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[16] Luhya is a amalgamation of about 21 subtribes in western Kenya. Just like many other tribes in Kenya, they are patriarchal, and polygamy is one way in which gender power imbalance is manifested to man’s favour. A man is expected to have a tight rein on his family, which reinforces his identity as a man. Interference in a family, especially from in-laws, is the biggest insult a man can experience.

or was it loneliness, or a need for intimacy that drove him to seek a partner? Much later he told me that he began seeing Winnie when it became clear that his first marriage had irreconcilably broken down. This contradicted the account he had given earlier on that he met Winnie 4 to 6 months after his wife deserted him. He told me that having Winnie as his "plan B" spouse was his way of minimizing the blow that the failed first marriage caused. While the transition from one marriage to the other went on smoothly, the admission that he approached the relationship with Winnie casually, without taking any HIV precautionary measures, was noteworthy. Nevertheless, it was not something that bothered him, as she was an "instant hit" and possessed attributes that his first wife lacked: respect, love, and adoration. Furthermore, since she was physically appealing and healthy looking, Estero did not struggle to reciprocate the love that Winnie showed him. In less than a month after the first wife left, Winnie and Estero moved in together andWinnie became pregnant almost immediately.

From his telling, it was evident that HIV was not on Estero's radar when he met and married Winnie. This made me wonder if he felt invincible to HIV or was ignorant about it. Did the pressure to remarry blind him to the need for an HIV test before moving in together? Was he confident in his own status? By Estero admitting that he learned a lot about Winnie when they were already married, he created an impression that a lot of things that happened to him in a short time span were unplanned.

Unplanned separation
Unplanned date
Unplanned marriage
Unplanned pregnancy
Unplanned relocation
Unplanned …

Unplanned
(Personal reflection)

Estero and Winnie's marriage was uneventful until 3 years later when Winnie was admitted to a hospital suffering from what later became advanced TB. During this admission, both Estero and Winnie were offered HIV tests, which came back positive for both of them. Estero had even more confessions to make during this conversation. When Winnie was expecting their first child, she declined an HIV test offered to her. As soon as the baby was born, it began to suffer ill health until it died of pneumonia 8 months later. Estero never questioned why Winnie refused an HIV test, as he too was not ready for an HIV test. Looking back now, Estero thought that his son was infected with HIV at birth or during breastfeeding, which explained the poor state of his infant's health. The diagnosis of pneumonia as the cause of death of his child may have been a *softer* way to refer to HIV infection. This time round, when the HIV test was offered to her, Winnie was too weak to resist or reject it.

> *In 2007, during one of the antenatal care clinics, Winnie was offered a routine HIV test, which she refused. Both of us were afraid to test at that time. Although the delivery went on well, the baby got ill immediately and died after 8 months. In August 2010, Winnie became gravely ill and while in the hospital, she was diagnosed with TB. The HIV nurses urged us to be tested for HIV and we consented; both of us turned out to be positive for HIV. We tried to be positive so that my wife could accept the treatment.*

Winnie's admission to the hospital opened a new chapter in Estero's life. It was through her sickness that he came to know his HIV status. It was here that Estero discovered that Winnie had secretly tested for HIV 2 weeks before her admission to the hospital. This left him wondering if and when Winnie knew her HIV status. Could that have been the reason why she declined the HIV test during the antenatal visit? Estero will never know. Since Winnie was gravely ill and required his support to recover from TB, Estero devoted all his energy, time, and resources to her care. Winnie's sickness also happened at a time when Estero abruptly lost his job as a clerk in a grains company. The job loss greatly affected his ability to care for and provide for Winnie, as he was the sole income earner.

> *The job loss, a sick wife, and an HIV diagnosis was taking a heavy toll on me. Initially, I chose to spare my wife the agony that I had lost my job; for I knew that it would stress her further [because she was very sick]. However, when we could not afford food, I had no choice. I decided to take my wife to her parents' place while I went to sort out my employment issues.*

The job loss was a clear blow to Estero's manhood, forcing him to abdicate his family responsibility and the care of his sick wife to his mother-in-law. Although it was culturally humiliating to ask his mother-in-law to take care of his family, Estero did not have much recourse. In his current state, Estero could not guarantee provision or protection for his family.

Estero never bothered to explore how he had contracted HIV and neither did he apportion blame to Winnie for the possibility of infecting him with HIV. Instead, he demonstrated love and solidarity with his wife through unwavering support as a patient admitted in the hospital. He suspended grieving his own HIV diagnosis to care for his sick wife. Estero's care towards his sick wife stood out in contrast with experiences I witnessed whereby men abandon their "unhealthy" HIV spouses the moment their HIV diagnosis is confirmed. Instead of sticking with their dying partners, they abandon them and move on with their lives.

> *When I came to see her the following day (in the hospital), her condition had deteriorated so much that I had to sleep by her bedside to care for her. At around one in the night, my wife passed away in my hands. This was too painful for me to bear. I had nowhere to go, had nothing to hold on to.*

Winnie died 2 months after she was diagnosed with HIV. To honor her memories, Estero desired to give her a decent burial on his rural farm, in line with the cultural obligations.

However, without the financial ability to do so, he settled for a municipal cemetery where poor people or those with no rural homes were buried. Although burying Winnie in a public cemetery was personally humiliating to Estero, he had unlimited access to her gravesite, as it was located near a footpath he used to walk home from town.

Winnie's death deprived Estero of companionship. Thus, Estero had to deal with HIV and look after his two children on his own. Immediately, not knowing what to make of the HIV infection, he sought professional help at Utumishi, the only AIDS service organization in the city. In this dialogical excerpt, Estero explains the process he undertook to receive HIV care.

> *After the death of my wife, I gathered courage and went to Utumishi for counseling where I found a good team of counselors, particularly Luanda, who really helped me through counseling to accept my status. Initially, I was reluctant to accept my HIV status. I was given Septrin to start off as they did blood work to determine the drug combinations appropriate for me. Two weeks later, I was put on antiretroviral medications because my CD 4 count was less than 92.*

Estero found it hard to deal with his HIV diagnosis at the time; uncertain of his family reaction would know his status. He was not certain how his extended family would react if they knew his HIV status. Hence, he chose to keep this information to himself.

> *First, I did not know how to handle this with my kids and my family and second, I had not accepted that I could be infected with HIV. I thought it happened to others as I had lost relatives through the same. Accepting my status was the most difficult part that was eating me from within. How I was to disclose to my children was another headache that was emotionally draining me. To date, I have not disclosed my HIV status to my children because I do not know how they would take it. I have been waiting for my daughter to finish form four[17], and because she is so close to me, I know telling her my HIV status before then would affect her school performance.*

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[17] Equivalent of Grade 12

Three years after he was diagnosed with HIV, he had still not disclosed his HIV status to significant others.

> *No, my family members do not know. My colleagues at my former place of work got to know when I was desperately pleading with my boss to rehire me. The secretary to my former boss also knows as well and she is the one who encouraged me and told me "why should you die, there are drugs to take. Take them and you will live your normal life." Other people who know my status are my work mates and some church members.*

The job loss and the death of his wife made Estero socioeconomically destitute. Living in the city was not an option, as he could not afford the expenses therein. Out of necessity, he moved upcountry to his ancestral home, away from friends and colleagues. While moving upcountry helped him to conceal his HIV status, it hindered him from receiving the support he needed to deal with HIV.

> *After the death of my wife, I retreated to my rural home as I was financially constrained to even afford school fees for my children. I was helping my dad at the farm, and life in the village was hard and expensive too. Every month, I was required to pick drugs in Ukweli. I did not want people to know my HIV status and I kept it as a secret to myself.*

Although life had turned out to be a nightmare for Estero, Utumishi somehow filled the void caused by Winnie's death, becoming a place where he came to receive free HIV care and other services. Once every 3 months, he traveled to Utumishi to refill his antiretroviral medications. The medications kept him alive, saving him from the physical deterioration from the HIV infection. He was grateful for this free service, which he knew he could not live without. In coming to Utumishi, judging from the multitude of people who came on a daily basis to receive diverse free services, I too acknowledged the enormous role it played in saving people from dying.

Utumishi has an unparalleled ambience
It is more than a building, it is a community

Where people are made whole
Hope restored
They call each other members
A sense of collegiality
Happiness and joy is not hidden from their faces
Utumishi saves them,
With free expensive medications
And they know it
Others work for Utumishi
They get and give care
(Field notes)

Estero lived with his father for 2 years in his upcountry home. Although I was initially baffled by the fact that he kept his HIV status to himself for this long, I acknowledged that there might have been merits for him to do so. The more I thought about this silence, the more I wondered how he related with his family members. I also wondered how this silence affected his overall wellbeing as a PHA. How might his life have differed had he chosen to live his HIV publicly? Would his family have been supportive and sympathetic towards him? I had many questions. Yet I acknowledged that the job loss and the demise of his wife may have taken a heavy toll on him and that perhaps silence was his only way of dealing with the losses that he experienced at the time.

Estero experienced a major turnaround when, in one of his visits to Utumishi to refill his HIV pills, he saw and applied for a research assistant position in an antiretroviral medication study program. Living with HIV and a willingness to publicly live and tell personal HIV experiences were the only prerequisites needed to apply for this position. When he was offered a job as a research assistant, he immediately relocated to Ukweli, relieved that he was finally able to support his family. In relocating to Ukweli city, Estero embarked on a journey to rebuild and restore his life that had been shattered by HIV infection, job loss, and the demise of his partner.

He expanded his social contacts to a local church where he became actively involved in its programs. Although not explicitly expressed, his association with the church somehow enabled him to deal with loneliness that he experienced by losing his wife. Networking with other PHAs within the church was also helpful in dealing with his own HIV status.

Although Estero had endeavored to embrace an HIV identity, a major obstacle was his inability to disclose his HIV status to significant others, particularly his immediate family members. By his own confession, Estero told me that he found it easier to share his HIV experiences with strangers like me, than people who knew him. He was particularly concerned that in disclosing his HIV status to his family, the stigma from them would be devastating and could shatter his ability to rebuild his life. Silence therefore had become intentional in order to protect him from such a possibility. In this telling, I somehow understood why he so jealously guarded his HIV from his father, even when they lived together. I composed this found poem[18] as I imagined how he justified his silence towards his family regarding his HIV status.

Father, brother, and children,
It is none of your business
To know
That in me lives a virus
A foreign virus

I want to speak, but cannot and will not
Till a time, appointed
Then, I open my heart to you
For now, I remain in darkness,
With my darkness

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[18] A found poem is derived from taking the text of a conversation and fashioning it into a poem.

It is the strangers I trust, and not you my children
Gossip, slander, stigma, from you
Would kill me,
My son and daughter,
I owe it to you, but wait a bit,

Till I gather the strength,
To face you
Will you judge me?
Will you still love me?
I am afraid, you might not!
(Personal reflection)

Although Estero felt that he had a right to conceal his HIV status to his family, he also felt as though he was acting unfairly to them. He nonetheless hoped to disclose his HIV status systematically, beginning with his children, and then to his extended family.

> *I will start with my close family members; my daughter and my son. One of these days, I will take them out for lunch then disclose to them. I hope that I can do this before the end of this year. This is because once she [daughter] completes high school, she will be staying with me and she will be seeing me take the drugs. . . . After disclosing to my children, I will tell my dad, who is the next closest family member. Later on, I will disclose to my estranged wife so that I can move on with my life. I do not think reconciliation with her will be possible. Letting her know of my HIV status will be a way of pushing her out of my life with finality. In a way, the fact that I have not disclosed and dealt with my wife has been a hindrance to my attempts at pursuing new relationships with women.*

While Estero knew that disclosing his HIV status to his family would be a major step in embracing his HIV identity, he remained apprehensive about how his family would react to the news of his HIV status. Surprisingly, he even felt obligated to disclose his HIV status to his estranged wife. In so doing, he hoped to give “closure” to that relationship. I wondered how he could achieve this closure by disclosing his HIV status to her. Were there signs that she was seeking reconciliation?

Since he was diagnosed with HIV, Estero told me that he had lost a considerable amount of weight that had significantly altered his physical appearance. He therefore lived in perpetual fear that his HIV diagnosis was obviously based on his physical appearance. To safeguard himself against being publicly identified as a PHA, he limited making contact with people outside of his work and church.

> *Physically, I have seen changes that make me nervous; I used to be little bulky, so when I am out there, when people ask me if I have lost weight, psychologically I feel as though people can see through me that I am living with HIV.*

The fear of his HIV status being inadvertently discovered by family and friends was almost pathological. He confided to me that I was the only person he had talked in-depth with about his HIV experiences and that he had no one he called a close friend. Since he moved back to the city, after securing a job as a research assistant, Estero remained isolated and did not entertain visitors in his home. As I attended to the story of social seclusion, I realized that somehow, not dealing with his HIV had allowed self-stigmatization to thrive, which was subconsciously exhibited through his utterances. From time to time, he told me that he perceived HIV infection as a “shortcoming,” an abnormality, and an inconvenience that had hindered him from asserting his old personality in the social situations he faced. For instance, although the urge to remarry was forever present before him, HIV infection hindered his ability to develop meaningful relationships with women that could lead to marriage. He feared that potential partners would reject him if they learned about his HIV status.

> *One of the things that I have not completely addressed is how to navigate relationships as a person living with HIV. I feel inhibited whenever I try to look for someone special. I still have not figured out how to explain to someone special about my HIV status. Therefore, I would have to rely on HIV positive women as potential partners, but I am yet to find someone close enough that I can relate to.*

In telling stories of self-isolation, I knew that it would be very insightful if I could visit with Estero in social places outside of his workplace. In so doing, I would hope to attain a deeper understanding of how his social life unfolded outside of Utumishi and the communal support available to him.

> We had planned to meet at Estero's house on a Friday afternoon when he was not working at the research program. Boarding a Matatu, a 14-seater bus, I headed towards his house, as he had directed me, about 5 kilometers north of Ukweli town. I found Estero waiting for me at the bus stop. He then led the way to his house, a one-room house conjoined with others in a row.
>
> This single room served as a kitchen, dining room, and bedroom. The utensils were scattered on the empty space on the right corner and a mattress laid on the floor. ATV was placed on a big carton on one edge of the room and a cooking pot sat on a stove next to his bed. A few used utensils were scattered on the right corner and a jar full of water stood nearby. Only a small space between the bed and the kitchen was left unoccupied. It was here that a stool was placed for me to sit. His clothes hung on the wall nails and the shoes lay haphazardly on the floor. He seemed to use the space well to hold all his earthly belongings in one single room. (Field notes)

Although Estero moved into this neighborhood 6 months earlier, he had yet to make any friends. He rarely spent his free time at home, and instead preferred to be at work or church. None of his workmates or family knew where he lived and I was the only visitor to grace his house. Seeing where and how he lived, I caught a glimpse of his socioeconomic situation. I wondered how he lived with his children: a teenage daughter and a college-going son. I knew that I was not at liberty to ask such intrusive questions.

Estero had promised to show me photos when I visited with him at his home. Reaching out for a laptop computer that was lying on the bed, he loaded an unlabeled compact disc (CD) onto the computer. He then invited me to explore the photos with him. To my surprise, the photos were of his wife's burial. He painstakingly explained each photograph in detail, which told a story of who came to the burial and how they were related to him or Winnie. Estero was standing emotionlessly next to a white coffin that carried the remains of his wife in most of the photos. A few times, he was captured holding onto the coffin by the handle. The emotional indifference he exhibited in these photos was so striking that I wondered if it was his way of concealing what he knew about the death of his spouse. As I looked at the photographs, I imagined the emotional upheavals that Estero might have experienced during this time; a time when he was newly diagnosed with HIV, experienced a job loss, and had just lost his dear wife.

I remained quiet throughout the viewing of the photos, not knowing what to say about them. Occasionally, Estero paused to sigh or catch a breath, and sipping black tea somehow helped him to carry on with this emotion-laden task. Although I was taken aback by the photos he showed me, I did not dare ask why he showed them to me. However, I could tell that he really wanted to watch them with someone. By explaining each photograph to me, he appeared as though he was assigning new meaning to each of them, rewriting the stories of living with Winnie in the process. From viewing these photos together, I could sense that the death of Winnie exposed his soft underbelly and reopened emotional and psychological wounds that his first failed marriage had inflicted him.

As Estero described each photo to me, I somehow understood why he posthumously showered Winnie with praise. She was storied as the only woman that he loved and who loved him unconditionally. He remembered Winnie as the one who transformed him from a hopeless and unhappy man on the verge of physical breakdown, to a fulfilled partner in a happy marriage.

She was a perfect partner for him and whenever Estero talked about Winnie, it was evident that they were glad to have found one another. Getting married to Winnie was the most beautiful thing that had ever happened to him or so he told me. Winnie treated him with respect and dignity, and for the first time in many years, he felt wanted and loved. Winnie got the best out of him and complimented him in every way as a loyal, beautiful, and entertaining wife. The 3 years they spent together were permanently engraved in his memory, temporarily erasing the 15 years of a "miserable" first marriage. By visiting her grave, Estero refreshed himself by reliving his memories of her. It was also his way of making sure that Winnie remained alive in his consciousness.

> *I always reflect those good moments that we have had together because compared to my first wife, she [Winnie] really loved me. I feel lots of attachment and love for her. Whenever I imagine another relationship with a woman, I always find myself comparing with the late wife. Yah, she is a reference point of sorts. Whenever I am walking to town, I am always interested in women who have a semblance of her, and I just find myself turning and gazing [at] them. I remember the good time we shared with her. She was a good entertainer in the house. She is the one who introduced me to Afro Cinemas. Whenever I watch them, I remember her and the moments we shared together. She meant so much to me.*

To be treasured as a man by Winnie, provided Estero with a sense of completeness and satisfaction. Sadly, these moments were short lived and are now a memory. However, they sustained him, speaking to him in times of loneliness and doubt; doubt about whether he would find love again. They also reminded him that true love was possible and could be found.

Visiting Estero's home deepened my understanding of the complexities that a lack of HIV disclosure brought to a PHA. The effort he made to make his HIV invisible was breathtaking too. Estero told me that he felt honored by my visit, which was an interlude to his loneliness. Although he wished to remarry, Estero told me that he lacked courage and strength to date women, as it would force him to disclose his HIV status.

Over time, Estero began to live positive narratives of HIV infection. He believed that HIV infection had made him more conscious of his health. He now attended regular health checkups and adopted healthier habits.

> *I think being infected with HIV had made me who I am now. I have known myself better. Before, I was careless with life, but now HIV infection has changed me. I am now more careful on what I eat, what I do, whom I go with, and whom I talk to. I take good care of my life and I am mindful not to cut my finger while cutting vegetables. I am time conscious and endeavor to be a more focused person in life.*

Estero's HIV diagnosis also provided him with moments of both spiritual and social awakenings. Prior to being diagnosed with HIV, Estero was a moderate alcoholic with no apparent spiritual and religious inclinations. However, soon after his HIV diagnosis, in the turbulences of life, he found religious involvement helpful in dealing with personal and social circumstances that HIV infection rendered him. Furthermore, he felt that he was a much more focused person in life as a result.

> *Since, I began attending church; I am focused in life and know what I want. I want to take the gospel out, using my powerful HIV testimony. With the little experience and training that I have gotten, I feel empowered by Utumishi to be effective in what I plan to do.*

Giving back to the community is another way Estero lives a positive HIV story. He volunteers in an HIV community based organization (CBO) in his hometown as a data clerk. During an informal lunch conversation, he told of his latest experiences as a volunteer in this CBO where he met a 13-year-old boy whose health was not improving, despite being on antiretroviral medication. On closer scrutiny of his care, Estero noted that the boy received only one type of medication as opposed to the triple therapy that was recommended. He convinced the CBO workers to transfer the boy to a health center where his care was optimized. He then used this opportunity to teach the CBO workers about the latest antiretroviral medications, drawing from the knowledge he acquired at Utumishi. The numerous volunteering opportunities at this CBO had cemented his reputation as reliable and dependable HIV educator, and a resource person.

Looking back after the 3 months of engagement with Estero, I acknowledged how privileged I was to have had listened to Estero's experiences. At the beginning of this study, I was apprehensive about whether a research engagement with Estero would succeed due to his formal demeanors that were intimidating at the time. However, to my surprise, he not only honored all of our appointments, but also liberally offered more information than I asked. As our relationship evolved, I increasingly let Estero lead the conversation. As an active listener, I was able to attend to the pertinent issues of his life. It was through active listening and attending to the stories that he deemed meaningful in his life that I acknowledged the nuanced roles that the two wives played in his life. This was instructive, given that he had a way of connecting his experiences with these two women as ones who had significantly shaped his life. Although the telling of experiences with each woman had a contrasting emotional commitment, through living and telling stories about them, he honored their memories and the roles they played in his life. These memories preoccupied him from letting the HIV experiences have complete control over his life.

The growth in our relationship was further spurred through the informal conversations over tea and lunches and in walking alongside him in social places. The more we met, the more we felt comfortable with each other and I was no longer afraid to ask direct questions about pertinent issues in his life. In every conversation, another layer of detail was added to what I already knew about his relationship with the two women in his life. In turn, I deeply understood who he was, and why he composed his life the way he did. Other stories that Estero lived and told related to his struggles with poverty and how he helplessly watched his son drop out of college due to the lack of college fees.

The growth of our relationship also emboldened me to confront troubling self-stigmatizing tendencies that I observed in Estero's telling. In one of our lunches together, I felt troubled by Estero's consistent self-stigmatizing statements about his inner feelings about HIV. Several times, I had heard him say in Kiswahili. "*Unajua Maina, mimi siko sawa*" (HIV infection makes me feel abnormal and impure). This to me meant that he had internalized a self-stigmatizing disposition, which made him feel abnormal or unwholesome die to a chronic illness. With such utterances, he constructed HIV as an inconvenience that greatly undermined his ability to make social progress. Unable to bear it any longer, I made my feelings known to him about the same, reminding him that the use of these phrases were self-stigmatizing and self-defeating. Although I felt outraged and disturbed for a moment I was awakened to the complexities and fluidity of his HIV identity. I wondered why I had become outraged by his comments. Was he aware that these comments were self-stigmatizing? Was it worth the risk of jeopardizing my relationship with him to discuss my feelings about his comments?

As we concluded our meetings, my awareness of how the psychosocial issues such as loneliness, self-acceptance, stigma, and disclosure of Estero's HIV status intersected with his social progress was heightened. I also realized the difficulties and the discomforts I faced when I had to make my feelings known to him about what I had come to understand about his life and the challenges he faced. I still wonder how his life would have unfolded had he disclosed his HIV status to his family.

Chapter 5: Narrative Account of Atoti

John, a senior official at the Utumishi AIDS service organization, assisted me with the recruitment of the study participants, by identifying them and making initial contact on my behalf. I was apprehensive to engage with female PHAs as participants who had been recommended by John. My initial concerns with having women as participants stemmed from my fear that they might feel uncomfortable sharing their stories with me in a relational way. John impressed on me the importance of having an equal number of male and female participants in my study. He was of the opinion that women's stories of living with HIV needed to be heard and I could not disagree with him on this matter.

After the initial hesitation, I invited Atoti to become one of my participants. For 3 days, I tried to connect with her on her cell phone without success. When I finally got in touch with her, Atoti told me she had travelled upcountry where the cellular signals were weak or absent. However, she had returned to Ukweli and offered to meet me at my convenience. We agreed to meet the following day at her workplace at Utumishi. On the meeting day, I arrived at the agreed place and time to find three women and a gentleman conversing at a nearby workstation. I was not sure if Atoti was among these three women. Since they were engaged in an animated conversation, I felt uncomfortable inquiring if they knew Atoti. Instead, I decided to call her on her cellphone to tell her I was around. As it turned out, she was among the group. Excusing herself, she answered her phone and I informed her I had arrived. Her friends escorted her with their eyes until she got to where I was standing. I wondered if she was being scrutinized or if they were just curious. Why was Atoti generating such attention from her colleagues?

We got to know one another in a formal way while still standing on the veranda. I asked her to identify a quiet place within the building where we could sit and go through research materials I had. She proposed that we occupy an empty bench around the corner, and although I had reservations about the privacy of the place she chose, she assured me that we would not be interrupted. Apparently, the volume of clients were at their lowest at this time of the day. Atoti read the information letter, after which I offered her a chance to ask questions about the project. She neither asked questions, nor sought clarifications about the project, agreeing with what I said without raising any objection. Once the research formalities were finalized, I let her return to her work, glad that our first encounter worked out well. We agreed to meet again 4 days later for our first conversation. Although I was glad that she agreed to participate in the project, I wondered if she had understood the project. Why did it seem so easy to recruit her? Was I expecting difficulties? I wondered.

Four days later, I arrived at Atoti's workstation about 08:30 a.m. in order to observe how her day unfolded, and perhaps observe her as she performed her duties and thereafter held our first research conversation. The waiting bay adjacent to Atoti's workstation was an open space where clients gathered for a morning HIV talk before they were dispersed to clinics. Three wooden benches joined to form a U shape and had a capacity of about 30 people. A long veranda that transected the building made the bay accessible to anyone that came to the building. Anyone sighted at the bay could be assumed to be living with HIV. Anyone passing by would easily notice me; those that recognized me waved their hands to greet me, and from the look on their faces, some wondered what I was doing there. Did they think I was a PHA waiting to receive HIV care? Aware of the perceptions that some held of me sitting in this space, I began to think about how we are framed and are storied from the spaces we occupy. How was this bay storied? What stories and histories existed in the spaces that the people inhabited? Although I did not know what services people were waiting for, I remembered my own experiences as a patient, and how vulnerable I felt when I had to depend on the advice and expertise of someone to alleviate my infirmity. I relived the many times I had to reveal the intimate details of my life, the many physical exams that I had undergone, and how I overcame my own need for privacy and comfort in order to be attended to by a clinician. Were they feeling the same?

Soon, I was joined by other clients; young and old, pregnant and nursing mothers. College students and pensioners sat patiently awaiting further guidance from Atoti and her colleagues, or so I thought. No one seemed to know the other, and they kept themselves busy by either gazing at passersby or scrolling through their cell phones. They were not bothered by the intrusive curious onlookers who often stopped to gaze at them. After all, no one was sick looking and no physical manifestations of HIV infection were evident on their bodies. I wondered if they were all taking antiretroviral medications.

I shifted my attention to a young beautiful woman in her mid-20' sitting across from me. She was immaculately dressed in a flowery navy blue dress and a matching light blue blouse. Her nails were well manicured and matched her light blue blouse. Her navy blue blazer sat on her loins and a leather designer handbag lay beside her legs. Holding a batch of car and door keys, she exhibited affluence and class. Occasionally texting with a palm-length black smartphone, she seemed preoccupied. I wondered who she was and why she was in the clinic. I also wondered about her lived experiences and how she would story herself. Was she seeking

HIV care or support? If she was positive, how did she story herself? How did she negotiate relationships? How did she perceive her future? I wondered.

On my left, a pregnant woman struggled to contain a 3-year-old boy who was nagging for attention. Seemingly exhausted due to her pregnancy, she did not seem to have the energy to contend with the boy and let him play at a safe distance within her sight. Occasionally, she arose to fetch the boy and make him sit next to her whenever he meandered away from her sight. I wondered if she too came to receive care for herself and her child. I wondered if she was aware of the prevention of maternal to child transmission of HIV program. To my extreme left, a man in the late 70s created a commotion when he tried to squeeze himself on a full bench. I offered my space to him, wondering who he was and why he had come. Was he infected with HIV, and if so, was he infected in old age or had he aged with HIV. The diversity of people seeking care and services at the clinic awoke me to the realization of how much things had changed or maybe they remained the same and had been invisible to me before. Every age group, gender, and social class seemed represented at the bay. Was this the face of Kenyans living with HIV?

Atoti arrived 1 hour late with sweat dripping from her face. It was obvious that she must have hurried to come. The clients had been waiting for close to an hour and she knew she was late to serve them. Acknowledging my presence, she hurriedly dropped her bag on the table, and grabbed her training manual entitled *13 messages for positive HIV living.* This manual, I came to learn later, covered critical lessons on HIV such as adherence to medication, sex, nutrition, and reproduction. Each day, before clients were dismissed to their respective clinics, Atoti gave a health talk. Visibly exhausted, she began to teach:

> *My name is Atoti and I am living with HIV. I was diagnosed in 2002, which is 11 years now. My husband was discordant at the time of diagnosis, but later seroconverted. I joined the psychosocial support group at Utumishi, which has helped me to accept myself and overcome stigma. This department is for clients like you and me. I plead that whatever we will share here, remains here. You can greet me if we meet outside there, but never raise HIV issues with me there.*

The talk lasted slightly less than 5 minutes. In it, she talked about the need to follow a physician's advice, bring the remaining HIV pills to the HIV clinic, and the importance of adherence to medication. She also reminded the clients of the importance of disclosing their HIV status to someone as a way to break the cycle of silence, to deal with self-stigmatization, and accept one's status. Atoti said that she had been disclosing her HIV status as part of her job since 2006, when she was hired by Utumishi as an HIV lay worker. The request to clients to keep her HIV information confidential outside of Utumishi made me wonder if she was only comfortable to share her experiences within Utumishi.

By referring to her audience as members, Atoti identified with them in their struggles with HIV, recognizing their shared challenges and experiences of living with HIV. In addition, given that some clients were new to the agency, this was Atoti's way of giving them assurance of her support as they navigated the complexities of Utumishi's bureaucratic system. From the look on her face, as she described how Utumishi saved her life, it was obvious that Atoti had a strong sentimental attachment to the agency. She described how Utumishi provided her with free antiretroviral medications as well as financial and social support at a time when she was desperate and downcast. Furthermore, by hiring her as an HIV lay worker, her source of her livelihood was assured.

During the HIV talk, Atoti freely talked about herself, her HIV status, and her experience of living with HIV, juxtaposing scientific HIV knowledge with exemplars from her own experiences. For instance, when talking about the need to have your CD 4 count checked before conceiving, Atoti related how she had to postpone conception for 6 months until her CD 4 counts improved. She only conceived when her physician permitted her to do so. By reliving her experiences, Atoti brought relevance and life to the lessons she taught. She also seemed to have memorized and internalized the lesson well and she rarely consulted her notes. Her intimate knowledge of Utumishi made her even more resourceful to the waiting clients. To me, by giving the HIV talk it seemed as if she created for herself a sacred space where she assumed the role of an expert educator, counselor, and resource person. There was an aura of confidence that surrounded her as she engaged with the clients. The way she explained medical and HIV jargon and technical terms using ethnically relevant metaphors was a pleasure to behold. Even as I was in awe of her oratory skills and depth of HIV knowledge, I wondered who the real Atoti was. Was I surprised or rattled by what I was hearing? Did Atoti's talk seem strange, yet familiar?

At about 11 am the bay was empty of clients. Atoti motioned me to meet her at the tent just across the veranda. The green and white striped tent sat conspicuously on an open field about 20 meters across from Atoti's office. Although it seemed less busy compared to other clinics, a few clients could be seen trickling into the site. She informed her colleague that she would be away from her desk to meet me for about half an hour. I followed, clasping my tape recorder and my notebook together. In the tent, we found two partitioned rooms; one was occupied and the other one was vacant. Lifting an untied canvas entrance, we made our way to the room that had a small table and two chairs. We hoped that we would not be disrupted for the time we would be there. Finally, I had a chance to spend time with Atoti and ask her whatever questions I had. However, some apprehension about how our research relationship would unfold remained;

> Knowing
> I am a man,
> She is a woman,
> I do not know,
> If she wanted to participate,
> How far she will go, in sharing her experiences
> Before she says enough!
> What stories will she tell?
> Who will she say I am to her family and friends?
> I am not sure about my own comfort asking her questions.
> (Personal reflection)

Atoti was not dismayed by my direct question about how she came to know her HIV status. I wondered if the indifference in her expression was a result of emotional desensitization resulting from personal experiences or from the work she did at Utumishi. Although the first conversations were primarily about her HIV status, other experiences were also lived and told in the course of our conversations. For coherence of her story, I have composed her accounts in a temporal way beginning with the pre-HIV stories she lived and told.

Atoti storied herself as a naïve, but sexually active teenage girl, growing up in a typical Kenyan home where she had enough support to see her through school. However, some of the choices she made at a tender age altered her life’s trajectory. While in Form 1 (Grade 9), she began a sexual relationship with her teacher, 12 years her senior, who also happened to be her village mate. While she enjoyed the favors that went with being a teacher’s girlfriend, at the time of our conversation, she felt that the teacher, who was in a position of trust, might have taken advantage of her naivety and inexperience to impregnate her twice, causing her to drop out of school.

> *I was 16 years when I joined Form 1 [Grade 9]. I was sexually active with a boyfriend. However, I began to date the teacher because he had the money to meet my needs. I now regret it because I never finished high school, yet my parents were able to pay for my school. When I got pregnant for the second time, he left teaching to pursue education at the university. While at the university, he got into a relationship with a university student whom he married. By now, I had no hopes of getting married to him. Out of frustrations, I decided to come to town to look for something to do.*

As Atoti shared narratives of her youth, I wondered if she comprehended the complexities of her sexuality, or the sexual changes that were happening to her at the time she became sexually active. I acknowledged that at 16 years, in a residential high school, away from the watchful eyes of her parents, Atoti may have felt some "freedom" to do whatever she liked or so she thought. In such environments, peer pressure and a lack of guidance and counselling may also have contributed to her engagement in risky and unsafe sexual practices that she was not prepared for. As Atoti described dropping out of school after becoming pregnant. I imagined the stigma, shame, and pressure that she may have experience as a result. In a community where single motherhood is stigmatized and frowned upon for "devaluing" the bridal price, it was not hard to imagine the quagmire her situation subjected her and her family to.

As Atoti narrated her stories as a student, her voice quivered, conveying bitterness and regret; bitterness about the father of her first two children, who seemingly took advantage of her naivety to impregnate her twice and not marry her. Also, bitterness with the lack of support from her father who did not persevere enough for her to remain in school. She seemed frustrated at the price she had to pay now to get a high school certificate she ought to have gotten 20 years ago. I wondered how her life would have become had she managed to finish high school.

Attending to Atoti's schooling experiences, reminded me of the often too common pitfalls that face girl children in Kenya. In my elementary schooling experiences, I was a desk mate to a girl named Jane who, despite being a brilliant child with a potentially bright future, could not proceed to high school due to lack of school fees. Frustrated, she was easily lured into marriage at an early age of 14. Four years later, she was a mother of three and divorced. Subsequently, she was forced to return to her parents' home. Being forced to return to her maiden home was perhaps the worst dishonor she could have experienced. Whenever I returned from school on vacation holidays, the sight of a once beautiful girl, now older than her years, wallowing in poverty as a village brewer was too painful to behold. For those that knew her, we restrained from judging her, stereotyping her or making mean references to her situation. Instead, we lent our ears when she came begging for money to buy her children's milk. As Atoti shared her teenage experiences, I wondered how to respond to them. Should I say, I am sorry or I understand? Or I hear you?
(Personal reflection).

At 18, Atoti, a mother of two and a school dropout, needed to mature quickly and assume parental and financial responsibilities for her two children. As a teenager, she headed to Ukweli city to seek employment opportunities. Becoming a nanny was the only plausible opportunity for her given her age, lack of academic qualifications, or professional experience. Due to a high demand for nanny services, she did not struggle to find a job as a nanny. Yet in moving away from home, Atoti was socially isolated, becoming even more susceptible to myriads of other social ills. As she told the experience of leaving home, I wondered what it meant for Atoti to take on adult responsibilities far away from home. Did she feel mature, accountable, and responsible?

Soon after relocating to Ukweli, Atoti met Martin, a widower, 12 years older than her. He lived in the same neighborhood as her sister whom she visited regularly. The more they saw each other, the more they fell in love or so it seemed. At the time, Atoti felt as though Martin loved her unconditionally, knowing that she was a single mother of two. Listening to how she fell for

Martin, I wondered if she was psychologically prepared to start a family, after enduring a turbulent relationship with her former teacher less than a year previously. Had she healed from the social scars that teenage pregnancy and being a school dropout inflicted on her? Was she even physically and mentally ready for marital commitments? I wondered.

> *He [Martin] was living in a similar estate with my sister. Whenever I was given a day off, I would go to visit my sister who was staying in the same estate as him. The more I visited, the more we became acquainted to one another. Later he told me that he wanted to marry me. I told him about the children I got while in school and that I had never been married.*

Without hesitation, Atoti accepted Martin's marriage proposal not long after they met. Her only condition was that he fulfill all the cultural rites of marriage, such as paying a visit to her parents and meeting the bridal price in full. Martin happily obliged to all her conditions, and in so doing, her position as Martin's legally married wife was cemented. As Atoti prepared to be Martin's wife, she gave an HIV test a thought but was unable to ask or make Martin undertake this test. Asking Martin to take an HIV test would have been an awkward request from her, as it could easily be translated as a lack of trust in his fidelity, health, or integrity. What would have happened had she asked? Did she feel pressured to marry? Atoti later told me that she restrained from asking Martin for an HIV test for fear that she might lose Martin. Furthermore, his healthy physical appearance gave her a sense of assurance that he was not infected with HIV. As Atoti recounted how she felt helpless to ask Martin for an HIV test, I recognized that the notion that just because someone does not physically look sick, is an excuse that is common when a person is reluctant to raise the issue of HIV with their partner.

Although Atoti was not sexually naïve at the time she met Martin, she firmly held that she was HIV negative at the time she got married to him. However, it was not clear from her telling if and when she undertook an HIV test. Two years after getting married, Atoti became pregnant. During a routine antenatal clinic, Atoti was tested for HIV, and the result was positive for HIV antibodies. At the time, she chose not to believe the results, deeming them false positive, and did not tell anyone about it. Four years after the first test, Atoti was pregnant again and a repeat test yielded the same result. This time, she believed the result and decided to inform the husband about her HIV status. When Martin took the HIV test, his came back negative for HIV antibodies.

> *In 2000, I went to the antenatal clinic for follow-up and I was tested for HIV as part of antenatal care. At that time, I never took the diagnosis seriously. I took it as a false positive and as such, I did not disclose to anyone. In 2004, I became expectant again and went to the antenatal clinic. I retested and was found to be HIV positive. It was then that I decided to have my husband tested for HIV who tested negative. I was really shocked by the turn of events; that I was HIV positive and my husband was not, and felt as though my world was crushing beneath my feet. I asked the physician how it was possible that I was infected with HIV, yet I was always faithful to him and he was negative.*

Atoti remained composed, emotionless, and indifferent as she relived her experiences of coming to know her HIV status. Her eyes remained focused on one spot on the table as though she was in deep contemplation, and only sighing intermittently. Even when she paused for a moment, I chose not to interrupt her so that she could organize and compose herself and take her story wherever she wanted to. However, the silences in between her telling spoke volumes about her internal processes as she recalled and shared these experiences. In addition, the ambience of the meeting place allowed her to vent and organize her thoughts without feeling rushed. I sat there, motionless as though I was absorbing the pain on her behalf. Somehow, I figured out that all that she needed in that moment was a presence, and I happened to be the one she poured out her heart to.

> *I was stressed by the news [HIV diagnosis] and also exhausted by my 6-month pregnancy. At night, my husband became physically and emotionally violent, accusing me of unfaithfulness as I was HIV positive, yet he was not. My neighbors heard all the commotions as our houses were crammed together. Three days after my diagnosis, my husband left our house to our rural home and told my in-laws and other relatives that I was infected with HIV. As a housewife with no income, fending for my family while pregnant became a nightmare. Unable to raise the rent, I decided to follow my husband to my in-laws. It was there that I learned how my husband's disclosure of my HIV status had damaged my name and reputation. My mother in-law stigmatized me by segregating me from my children, made sure I ate in seclusion, away from everyone else including my own children.*
>
> *Within the week of separation, while still at my in-laws place, I learned that my husband had left for a job in another town and immediately married another woman; my HIV infection being the justification of his actions. It was an unbearable 1-week stay at my in-laws and I was forced to come back to Ukweli, where our home was. My neighbors who had since learned of my HIV status, taunted me with songs and refused to share toilet facilities with me, alleging that I would infect them with HIV. They played a popular HIV song of the time called* ***Dunia mbaya***[19]*whenever I was around. The stigma I experienced from my neighbors depressed and paralyzed my will to live. Worse, I had no one to lean on. Thereafter, the landlord advised me to move out of my house under pressure from the neighbors. He gave me some money to pay for my rent at a different place. Devastated and poor, I moved to a mud walled house that had no toilet.*

The social consequences of HIV infection were abrupt for Atoti and perhaps the most significant event in the immediate post-HIV diagnosis experience. Stigma, violence, discrimination, and desertion were the most traumatic experiences that followed her HIV diagnosis. In the wake of Martin's desertion, Atoti was left to fight her HIV alone and her vulnerability as a PHA was at an all-time high.

HIV positive,
Pregnant,

---

[19] Dunia Mbaya can be loosely translated to mean that the world had turned evil. It was one of the earliest songs to be produced when HIV infection was spreading. The song was often played in national radio stations, and in almost all public spaces, warning people about the dangers of HIV.

Dejected,
Poor,
No friends,
Alone,
Hopeless,
Homeless,
Betrayed,
Stigmatized,
Discriminated,
Hated!

In Atoti's elaborate sharing of her experiences, she painted a grim picture of what befell her immediately after her diagnosis became public. Betrayal from her partner and stigma from family and friends drove a wedge between her and the people she loved and cared for, leaving her alone to fight for whatever fate awaited her. How did they expect her to handle the HIV crisis as a pregnant mother with young children on her own? Where was humanity, compassion, and mercy? I wondered. Yet, in all these stories, Atoti maintained her position that she was faithful to Martin throughout their marriage.

So far, this was perhaps the hardest moment of my conversations with Atoti. In reliving these moments, it was as though she was tormented by her memory as she remembered how defenseless she was in the face of the family and communal onslaught when her HIV status became public. To be mocked with a song such as ***dunia mbaya (the world is rotten)*** (July, n.d) as happened to Atoti demonstrated the highest level of stigma possible. This song, which debuted in the 1980s to warn and educate the public about the lethality of HIV and to warn against reckless living, featured haunting imageries of dying AIDS patients. It quickly transformed into a condemning song that seemed to point fingers, blaming or incriminating anyone suspected of being infected with HIV. Subsequently, it invited fear and dread rather than informing people about how to prevent or respond to HIV infection. Atoti's neighbors knowingly and deliberately tormented her with this song, to perhaps unsettle her or express disgust at her presence in their midst. They succeeded when they prevailed on the landlord to kick her out of the rented house.

Being disowned by loved ones due to HIV infection remains a common occurrence in many parts of Kenya due to misinformation about HIV infection. Although it is not possible to quantify the extent to which this practice has lingered, physical isolation is still practiced due to a belief that HIV can be contracted through physical contact. Without knowing, this isolation dehumanizes a person as a worthless member of the society. I imagined how Atoti's grievances towards HIV infection might have been. It:

Broke my family
Made me a destitute
Made me homeless
Made me loveless
Changed my destiny
Tarnished my name
Humiliated me
Banished me from the community
Stole my dignity
(Found poem)

Having been deserted by her partner, banished from her rural home, and evicted from her rented house, Atoti became homeless and had no dignity left to preserve. The pressure to survive and to provide for her three children was immense, forcing her to do the unthinkable.

> *Life with no source of income was getting harder by the day. Poverty drove me to prostitution and drinking illicit brews. I withdrew my first born son from school to take care of my other children so that I can concentrate on my brewing business. When not selling the brew, I would go to town for sex work.*

Atoti candidly told me that she engaged in prostitution for survival purposes, as there were no other options for her to provide for her family. She suffered other difficult experiences while engaged in the sex business that were traumatic to discuss (and which I am not at liberty to write about). She asked that I maintain the utmost confidentiality regarding these experiences. Whenever I thought about these stories, my heart was filled with sadness, unable to fully grasp the extent of the ordeal she had to endure in order for her family to live. Due to the emotional intensity of the conversation as she lived and told of her experiences of coming to know her HIV status, I often wondered what my role was in that moment.

> What do we become as researchers to our participants? That question has stayed with me today after hearing the accounts of Atoti's life engaging in prostitution for survival. What is too much to hear? I am not sure I was prepared for what I was hearing. I felt as though I was an emotional hole, as though Atoti really wanted to offload stuff from her heart, and I became the person of convenience. The extent to which Atoti opened her life to me, within our first formal conversation, made me wonder if my role to her had changed from a researcher to someone who engaged in therapeutic interactions. I thought that the details she shared were too deep and the fact that I was not supposed to tell anyone left me even more puzzled. How can I continue to hear her stories when she had told me things that her husband should not know? (Field notes).

Although I have read and watched TV reports on people who engage in transactional sex for survival purposes, listening to someone share her experiences in the manner Atoti did was transforming. I became even more respectful of who she was. Despite Atoti doing the unthinkable for survival purposes, robbing her of dignity and self-pride, she was clear that the welfare of her children took precedence. While her commitment to her children was never in doubt, withdrawing her children from school to serve in her brewing business was heartbreaking. Yet, even when such a confession was troubling, I empathetically recognized the direness of the circumstances she was confronted with.

An unexpected calamity within the family further strained the balance that Atoti had struck to look after and provide for the children. Her youngest son fell ill abruptly and needed to be admitted to a hospital. She accompanied him to the hospital where he was admitted for 2 months. Atoti left the other children on their own, under the care of neighbors and strangers. Even under such circumstances, Atoti demonstrated her love and commitment to her children by walking 5 kilometers every day from hospital to her home, carrying her portion of hospital food to share with the children. Once she was satisfied that they were nourished, she made a return trek to the hospital, to be with her sick son. This was her commitment for the 2 months that her sick son was in the hospital. Although this was the best care and love she could offer her children, given the circumstances, she was tormented by the fear of the unknown befalling her children at night. This fear kept her awake most nights. This hospital admission also led to a collapse of her brewing business.

> *One day, my youngest son became gravely ill and required admission to the hospital; immediately, he was put on oxygen. I spent the nights in the hospital to care for him. I left the other children alone to fend for themselves, although the older one knew how to sell the illicit brew. The sick child was weaned off oxygen after 2 weeks and made full recovery. Although we were discharged home, we could not raise the hospital fees. Not even my husband and in-laws came to our aid at the hour of need. At home, my two other children were languishing in poverty. The brew business ran down since the suppliers could not deal with my children. I resulted to sharing my hospital food with them so that they can survive.*

As she told this experience, I somehow grasped the intensity of devotion to her children and the difficult circumstances in which she brought them up. Although her sick son recovered within 2 weeks of admission, he was kept in the hospital for 2 months because Atoti was unable to pay for his medical expenses. In response to this situation, Atoti exhibited great courage to keep her composure in the midst of immense personal and social pressures. Since a majority of her HIV experiences were told during our first conversation, letting her bring forth these difficult stories without interruption seemed therapeutic to her. Nodding occasionally and making encouraging facial expressions was my way of being present as she lived and told of her experiences.

Atoti's face glowed when she began to talk about how she turned her life around. By chance, while detained at the hospital, she met and shared her experiences with Jane, a nurse working at Utumishi who had come to minster to the sick on a Sunday morning. Jane believed her story and the following day, she presented Atoti's case to the unit social worker who confirmed that she was living in poverty and unable to pay for her son's medical bills. Subsequently, she had the medical fees waived. Besides arranging for the waiver of the medical bills, Jane also gave Atoti money for groceries and money to use as capital to start a business.

> *I met a nurse called Jane at the hospital where my son was admitted and I explained my state to her. Jane approached the unit's social worker and told her my story. Upon investigation, they found out that my story was genuine. As a result, the medical fees were waived and we were allowed to leave the hospital. Jane then took me for shopping and bought me basic necessities worth Kenyan Shillings 3000[CAD 40]. She also gave me Kenyan Shillings 1000[CAD 12] to start an alternative business, challenging me to change my lifestyle as I had become a Christian. I was determined to turn my life around, and began attending a HIV support group meeting at Utumishi.*

Through Jane, Atoti learned about the HIV services offered by Utumishi, a local AIDS service organization where Jane worked. Atoti also embraced the Christian faith, which helped her network with other PHAs and accept herself. With Jane's support and encouragement, Atoti abandoned her work as a prostitute and started a small business. She experienced a financial turnaround that enabled her to reenroll her children in school and buy land where their house stood. Atoti was forever grateful to Jane for believing and acting on her story. Undoubtedly, Jane helped her rediscover life's purpose by providing social, spiritual, and financial support. In Jane, Atoti gained a confidant, a close friend, and spiritual leader.

Taking Jane's advice, Atoti enrolled in the HIV support group that met once a week. These meetings created an environment where Atoti learned about other PHAs' experience. She was greatly encouraged to learn that other PHAs had more complicated lives than she had, yet they lived positively with HIV. Atoti was comforted by their stories and the friendship that she developed in the support group meetings. Gradually, she also embraced her HIV status and began to share her HIV story.

> *I was amazed at the ease in which people living with HIV gladly shared their lived experiences. I learned that the majority of them were having grave challenges. Some had lost their spouses to death or abandonment, were single mothers and others had many dependents to look after. Others were living as discordant couples. I also learned how they lived positively with HIV and how they sustained themselves. I was transformed by these meetings and got empowered to look for informal employment to support me and my children. I completely stopped illicit brews business and prostitution. I reenrolled my children to school, regained lost weight and my CD 4 count went up.*

In the support groups, Atoti developed a sense of belonging by networking with people whose experiences were similar to hers. Encouraged by her new association with other PHAs, Atoti too began to share her own HIV experiences with them and, with time, her self-image and self-esteem blossomed. With the support of the newly found friends in the church and in the support group, Atoti began to find her HIV burden bearable. With time, she also became an expert communicator in HIV who readily shared her experiences of living with HIV in public places. In 2006, Utumishi hired Atoti as an HIV lay worker, having proven herself as an HIV educator and advocate. This job drastically and permanently altered Atoti's socioeconomic fortunes.

> *You know that Utumishi was created to cater to people living with HIV. It is concerned with our holistic welfare such as free antiretroviral treatment and socioeconomic support. To me Utumishi is my second god. By giving me a chance to live, my children,*

> *and those of people living with HIV are not orphaned. I have the strength to care for my children, my life is better than it was when I was HIV negative. My strength is now back and as a result, have committed to working for my clients that are living with HIV.*

As a way to give back to the community for the support she received from Utumishi, Atoti became a community liaison person for the organization. By engaging in community HIV work, Atoti hoped that those that were either diagnosed or suspected of having HIV could receive the help she had received. Her community outreach extended to her former neighbors and landlord whom she supported without prejudice and impartiality, despite being taunted by them when she was infected with HIV.

> *In my work, I have met and served many people living with HIV including the landlord and my former tenants that turned their back on me when I became HIV positive. By working at Utumishi, I am able to assist anyone living with HIV. All the people I have introduced to Utumishi have recovered from their illnesses and regained their strength.*

Atoti transcended her own need for privacy by compassionately reaching out to those she felt should have an HIV test or PHAs struggling to accept their HIV status.

Just as Atoti was settling down as a single mother, Martin came back in to her life, five years after he deserted her. By this time, Martin was in an advanced stage of HIV infection. Atoti was visibly enraged to see him, recalling how he violated her at a time she needed him most. The found poem below is the expression of Atoti's mental processes when she saw Martin standing at the door.

After 5 years, at 7 p.m. he came back,
My husband came back home
Filled with rage, I wanted him out, out of my life
I did not need him-anymore
My children, pleaded-accept him back
He is our daddy, and your husband
He seems sick-and dying

What happened to you, my darling, you are so wasted!
I have been struck, just like you with the deadly virus
Why do you come now?
To die in your arms, I have stories to tell, but not now
Would you let me in, in your house and heart………….
No,
Yes
No,
Yes, mummy, let him in!

Atoti admitted that she was not sure what to do with Martin when he showed up at her door. She reluctantly accepted him, yielding from the pressure from her children to do so. Although this reunion opened a new chapter to Atoti, it also tested Atoti's forgiveness, accommodation, and patience. While Atoti took a long time to forgive him for the misery he had caused her, she knew that it was the right thing to do and was consistent with her Christian faith. Furthermore, given his physical state, any delay in taking action would have been fatal. As Atoti agonized with this narrative, I wondered if it would have been OK for Atoti not to accept him back. Was she morally obliged to take him in, considering what he subjected her to?

With the support of her church members and her peers, Atoti found forgiveness possible. She was urged not to repay good for evil; instead, as a way to live her Christian faith to show unconditional love to her once estranged, but now dying husband. I imagined, from bible verse, what Atoti was called upon to do in order to accommodate Martin. It was all about love.

Love is patient,
Love is kind.
It does not envy,
It does not boast,
It is not proud.
It does not dishonor others,
It is not self-seeking,
It is not easily angered,
It keeps no record of wrongs.

Love does not delight in evil but rejoices with the truth.
It always protects,
Always trusts,
Always hopes,
Always perseveres
Love never fails
(Bible verse)

The reunion between Atoti and her husband Martin reminded me of a song I grew up hearing, warning young men against chasing vanities in the cities. In *Muka mukuru achokagirirwo na maithori*[20],[21] *the* artist eulogized a man's adventure to the city to pursue a life of pleasure and happiness having denounced his barren wife. Overwhelmed by the city's pleasures and unable to exercise self-control, he indulged with younger women, and in no time all, his wealth was squandered. As long as he had the money, he was attractive, witty, and funny to be around, but loathed when broke.

His short-lived friends left him poor and destitute and for many years, he avoided going home. He was too ashamed to admit that he erred in his judgment to leave his wife in the first place. He lived on the streets, surviving on the handouts of passersby, doing odd jobs, and salvaging dump yards for leftover food. After a long time, he realized how wasted he had become and decided to go back to his community and see if his wife would recognize and perhaps accept him.

Unsure about whether his wife was alive, remarried, or relocated, he hoped against hope that he would somehow find her. With no pride and dignity left, he approached the footpath leading to his homestead, carrying his personal belongings in an old tattered plastic bag. Seeing his wife splitting firewood at the place where he used to milk his cow, he yelled and cried loudly, attracting the attention of villagers. He refused to come to the compound and demanded that his wife come and publicly forgive him, assuring him that she will not reprimand him.

The song was similar to Martin's conduct; he left his wife to chase vanities ostensibly because of Atoti's HIV status only to come back dying from the same disease as Atoti. I wondered how much Atoti struggled to forgive, accommodate, and accept her husband in that moment (Personal reflection).

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[20] DeMatthew, P (n.d). Muka Mukuru. Retrieved from https://www.youtube.com/watch?v=d9C8gMfzwSQ

[21] Loose translation. The first wife for a polygamous man, through despised, is the only real treasure.

As Atoti narrated Martin's return to her, I wondered how he managed to find her new home. I imagined him knocking on former neighbors' doors asking if they knew Atoti and where she had moved. I wondered what the neighbors thought about him abandoning his family, and then reappearing when he was sick and dying. In what state was he expecting to find his family? His return plunged Atoti and her family in to the unfamiliar.

> *On his first night with us, he slept on the chair. He was still sleeping the following day when I came back from my chores. He had not taken breakfast and was too sick to even walk. I learned that the wife he married after he left me died of HIV not long after they met. When he became too weak, he went to his rural home to be nursed by his mother. Instead, she chased him to come and die with his "HIV positive wife."*
>
> *Knowing that he was about to die, I organized transport to take him to Utumishi. There, he was confirmed to be infected with HIV. He had a CD 4 count of 28 and was immediately started on antiretroviral medications.*
>
> *I forgave him for all that he had done to me, remembering our first love. After all, he was the father of my children and I would not stand to see him die. He stayed in the hospital for about a month until he began to regain weight. I became his closest friend, and nursed him back to health.*

Atoti's commitment to HIV clients was tested when her husband returned. By overcoming the bitterness that his desertion and violations caused her, she got her husband back, a humble and a repentant man. Seeing Atoti's joy when she talked about her restored familial relationship gave me an impetus to visit with her at their home. I knew that a home visit would help me get some clarity on the many questions I had regarding Atoti's social life. Even as I was embarking on the visit to her home, I was not sure what to make of my feelings towards Martin, considering the misery he had caused Atoti when she was diagnosed with HIV. When I made a proposal to visit, Atoti was very enthusiastic about it.

Being mindful to keep silent regarding Atoti's HIV stories, I arrived at her home to find the family busy with diverse household chores. The homestead comprised two semi-permanent walled houses that sat on a half of an acre on top of a hill. I wanted to sit outside the house to enjoy the panoramic view of the community, but Atoti would not hear of it. She wanted me in her house where her husband was waiting to meet me. The living room, where her husband sat, was well organized with a matching couch and a loveseat covered with white cloth. The well plastered inner walls and floor gave this mud walled house a modern feeling. Atoti ordered one of her children to make tea for us, and then sat beside her husband, clasping his hand tight.

Atoti's face radiated with joy as she introduced Martin to me as *Mzee wa nyumba,* a respectful way for the head of family. I had rapport with Martin almost immediately, talking about a wide range of issues including contemporary political and economic ones. During this conversation I learned that Martin had a vested interest in Atoti's education. At the time, she was sitting for her national high school diploma exam. I could see why Martin was keen on Atoti's academic progress. As the sole bread earner in the family, Atoti guided the aspiration and the future of the family. After graduating from high school, Atoti hoped to pursue a national diploma in counseling psychology and become a counsellor at Utumishi. Although Atoti provided for the family and owned the property where their home was constructed, she obeyed her husband, according to her cultural and religious expectations. She had enrolled her husband in a vocational training course to make him economically productive.

> *With my savings, I enrolled my husband to a driving school to train as a driver. He did well in the training and now has a certificate of good conduct and a clean record, even though he is still unemployed.*

Atoti and Martin looked after nine children, three of whom were orphans, whose parents died of HIV infection. Atoti told me that due to the large size of the family, they could not afford three meals per day and occasionally lived on one meal a day. Visiting with them and seeing how and where they lived, I appreciated her dedication to her family and witnessed how she was rebuilding her relationship with her husband. During my 2-hour visit, I found Martin pleasant and approachable, a complete contrast to the stories I had heard earlier about him from Atoti. Nothing that Atoti had told me about him resonated with the Martin I met; gentle, humble, engaging, and polite. Yet, I did not know what to make of the stories Atoti had told me about Martin. Did they affect my judgment towards him?

> Today, when I met Martin, I was not sure what to make of him from the stories that Atoti had told me, of his cruel and violent past. He seemed the exact opposite of what Atoti had painted him; gentle, calm and warm and with a harmless demeanor. Looking back now as I write, I felt that hearing negative and destructive stories of Martin from his spouse had impacted my perception of him. In the moment when I was in Martin's presence, I had to wear a façade and not betray what I knew about him. Aware that each story has two sides to it, I resisted the temptation to seek clarification and answers from Martin regarding what I had heard, as he was not my participant. Yet I wondered if that was part of why I had come to visit.
>
> I was also troubled to know so much about him that somehow, my objectivity was blurred to an extent that I was no longer certain if I attended his stories and his person the way I would have liked. While I worked hard to remain objective to what he was saying to me, the fact that he did not know what Atoti had told me about him made it easier to engage.
>
> Martin did not ask why I had visited them. I wondered if he knew my research interest. I wondered how Atoti had introduced me to him. Who was I when I paid them a visit? A friend, a researcher, stranger? My assumption that he did not think I knew their HIV status was good for our bonding. (Field notes).

Although Atoti was generous with information about her life, ethical moments arose when I did not know what to do. For instance, because Atoti had storied Martin unfavorably, I struggled to attend to his being when I made the home visit. The fact that I knew intimate details of her dark past that Martin did not know, and which I was told to keep secret, added to this awkwardness.

As my time drew near to return to Canada, I invited Atoti for lunch conversations soon after she finished writing her exams. Eating together provided particularly significant moments in our research relationship and Atoti was even more relaxed and engaging. I was excited about the possibilities we were creating together, sharing more social moments at diverse places. In these conversations, HIV stories were not afforded more importance than other life events such as her daily struggles with poverty, parenting, and social issues. During these social encounters, Atoti began to live a positive HIV story. Rather than seeing HIV as an adversary, as it was in the previous narratives, she storied HIV as a gateway to her financial security and social emancipation. HIV infection also created a network of friends for her with whom she had found support in embracing her HIV identity.

Chapter 6: Narrative Account for Nelly

Nelly was the second woman John introduced to me as a potential participant in the research project. Two days after John shared her contact details with me, I contacted her on her cell phone, requesting an appointment to meet. Over the phone Nelly gave me directions to her office which was easy to find by following the signs within the Utumishi building. I waited for her on a bench adjacent to her office as she was attending to a client. Five minutes later Nelly came out to meet me, and after exchanging formal pleasantries, she ushered me into her moderately sized, fully furnished office. I was impressed by the general organization of the office which had two large desks that occupied most of the floor space, leaving a narrow passage between them. At the corner of the office, huge shelves with large coded files were methodically organized, giving an impression that big projects were coordinated through her office. I wondered what these files contained. Other small files and papers littered the desks, creating an impression that Nelly and her partner may not have been in the office recently. Nelly provided a seat and invited me to sit down.

Even without knowing who Nelly was, I imagined that Nelly’s status in the organization was significant considering that she was allocated an office space, an executive chair, and a desktop computer. Just as we were settling down to talk, a client knocked and opened the door, and without hesitation, made her way toward Nelly. I was not sure if this was an impromptu visit or a scheduled appointment, but I was aware that we were meeting during Nelly’s official working hours. Nelly encouraged me to stay, advising me that there might never be a perfect time to meet without being interrupted by clients. I was concerned that my presence might be an obstacle to a therapeutic connection between Nelly and her visitor, named June.

I was amazed by the drama that the meeting of these two women created. They embraced each other so tightly that they smelled each other's breath. Tapping each other's shoulders and then exchanging an exaggerated hand shake, the shrieks of laughter and happiness filled the room. Their warmth to one another implied a well cultivated and nurtured relationship. Clearly, their relationship ran deep, or so I thought. I wondered who they were to each other. Were they related? I later learned that June and Nelly met in the HIV support group meetings as participants and had since kept in touch. Whenever June came to Utumishi, she met with Nelly to update her on her life and that of her children. On this particular day, June's concerns were about her 17-year-old daughter who recently enrolled in a residential high school. June's daughter was also HIV positive but her mother had not fully disclosed to her daughter the nature of her disease, apart from the fact that she needed to take medications for life. Yet, although a 17-year-old woman might be regarded as mature enough to comprehend and process such information, I presumed that there was a legitimate reason why she was not fully informed about her condition.

June and her daughter had not lived apart until she left for secondary school. As such, June had always shielded her daughter from the social effects of HIV infection. Out of necessity, June disclosed her daughter's HIV status to the school administration in order for her to be supported to adhere to her treatment. As she was sharing her experiences, I began to wonder how June's daughter might be treated by those who knew her status. Was she the first student to be admitted as a known person living with HIV in that school? Who else knew about her HIV status that perhaps should not know? What did she tell the teachers when she missed classes to attend HIV appointments? How about her fellow students? How did she maintain confidentiality?

Nelly reminded June to enroll her daughter in a disclosure camp during the holiday vacations. This particular camp was for teenagers living with HIV who had never been told about their HIV status. As she was talking with June, it was evident that Nelly fully engaged with her client and gave her undivided attention. Her voice was laden with compassion and concern for her client, often leaning towards her and maintaining eye contact throughout the meeting. After June left, Nelly told me the details of the work she did in the office. As an HIV lay worker, Nelly was privileged to know clients intimately, and with some, she was able to pursue personal relationships.

Nelly worked primarily with children, teenagers, and young adults living with HIV. Her personal experiences of living with HIV as a single mother of two gave her insight into supporting people in similar situations. She believed that children living with HIV were a unique group requiring patience and understanding. Even before we began talking about my work, from listening to the conversation between Nelly and June and the briefing of her work, I felt as though I had come to know important things about Nelly, especially her passion to work as a child support worker.

Signing up for this research was a formality for Nelly who told me that she had made up her mind to participate in this study after John approached her. I wondered what motivated her to enlist. Did she fear John or did she do this out of respect to him? Did she understand the project well enough? Nonetheless, I explained in detail what this research was all about, glad that Nelly was quick to sign up. By now, clients had begun milling around her door; others impatiently knocked and half opened her office door to register their presence. I let her carry on with her job after securing an appointment for our first conversation.

Two days after our initial meeting, I met Nelly for our first formal research conversation at Utumishi. We met at a tent, outside of the Utumishi building, which was a convenient place for our meetings. It was a quiet spot and I was not worried that we would be interrupted in the course of our conversations. From her stories, I knew that she enjoyed working with children. Nelly gave numerous exemplars and references about her work, laden with strong convictions and passion. I often wondered if this passion had anything to do with her personal experiences as a mother or from the years of working at Utumishi.

> *I work in the psychosocial and peer support group and as a PHA, I understand the feelings PHA have because I experienced the pain of HIV testing and subsequent anguish. I am able to empathize with our clients to help them accept their disease and live positively. Acceptance is what they need, because some are orphans, who acquired HIV through non-sexual means. It is thus our responsibility to make them live normal lives as well.*

Nelly's identity as a person living with HIV was interwoven with her experiences as a mother, a wife, and her struggles of coming to know and accept her HIV status. Her joy in mothering children who were HIV negative at a time when she had already been diagnosed with HIV represented one of her remarkable moments. Knowing that her children would not be burdened by HIV as they grew up was an indescribable blessing. She now felt compelled to teach HIV positive pregnant mothers to adhere to the protocols to prevent maternal to child transmission of HIV (PMTCT). Over time, I learned that her personal experiences as a PHA had made her tender hearted, kind, and compassionate. Her greatest satisfaction and joy was to meet the needs of her clients in the best way she could. Although Nelly had highs and lows during her 7 years working with children PHAs at Utumishi, to her each day was an opportunity to make a difference in their lives.

Nelly associated her stories to live by with the poverty she had experienced in her childhood. Reflecting on the impact of her formative years allowed her to locate her HIV experiences in context. As the last born in a family of five, Nelly grew up in a loving family, struggling with poverty. When the time came for her to attend high school, her family could not raise the needed fees. Missing a high school education had both short term and long-term ramifications in her life. In the short term, Nelly missed the experiences, memories, knowledge, and growth that came with attending secondary school. In the long term, Nelly missed opportunities that a high school certificate would have afforded her including pursuing a college education and accessing some types of employment. Although she grew up in poverty and had to follow a different life trajectory than she had envisioned, Nelly somehow compensated for the lost opportunity to pursue higher education. She enrolled in a community college to pursue a certificate in secretarial studies.

> *My cousin got me a vacancy to train as a secretary in a community college. I was the youngest in the class because I enrolled straight from class 8 (Grade 8). I got my secretarial certificate 1 year later, but I needed an identity card to secure employment. I went to my pastor to alter my baptism card[22] in order to apply for an identity card. My uncle then secured me a secretarial job at one of the high schools near our home.*

Attending to Nelly's story of her formative years, I was intrigued to learn that she was able to pursue a post-secondary diploma as a primary school dropout. Against all odds, Nelly succeeded where many thought she would fail, surprising even herself at how fast she mastered the subject. When she completed her certificate, Nelly was still too young to be issued a national identity card, leaving her with no alternative but to manipulate her age to appear older. With an

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[22] Baptismal card is often used as a form of identification to apply for a national identity card.

identity card, Nelly began to enjoy adult privileges such as opening a bank account and seeking formal employment.

With a stable income, Nelly looked forward to starting her own family in line with expectations of her community. She could not remember exactly how old she was when a young man named Moses appeared in her life. Nelly was not even certain where they met, but in an instant, she was convinced that he possessed the qualities of a man to spend her life with. Furthermore, as a bible school graduate, Nelly hoped he could use his biblical knowledge to build their marriage on a solid Christian foundation. Therefore, when Moses proposed to marry Nelly, she found him irresistible. In Moses, she had a man who would stand with her in *sickness and in health, in poverty and in riches, until death do them part.* She hoped that their marriage would be an example to other aspiring youth in her church.

In our first conversation, Nelly did not provide details of her wedding to Moses, leaving me to wonder about this deafening silence. Naturally, I was expecting that she would relive her cherished wedding moments as many people often do. I imagined her wedding must have been a typical community affair that characterizes many weddings in Kenya. As a day full of happiness, the bride is showered with presents, gifts, and blessings to start a new life. Symbolic gifts such as beds, cooking pots, and other kitchen utensils are given, speeches are made, and food is often in abundance. Her relocation to Ukweli where Moses worked was the only detail that was forthcoming about her wedding to Moses.

As our relationship grew, I understood why Nelly was hesitant to talk about her marriage with Moses at the beginning of our conversation. Her marriage to Moses did not unfold as she had intended and instead became a source of pain, suffering, and anguish. Any attempt to relive it reopened unhealed wounds and greatly retraumatised her. Whenever she recalled her marriage to Moses, she was reminded of betrayal, infidelity, and violence that Moses subjected her to. The stigma of failure and divorce, the shattered identity, image, and esteem that accompanied her failed marriage hampered the development of her identity as a Christian woman. By failing in her marriage, Nelly felt as though she had let her church and her community down.

> *They knew well that I did a church wedding and relocated to Ukweli. A few know a bit about my failed marriage, but I did not want anyone to know the details of it. To me as a Christian, it was very shameful as I was a leader in church who was involved in matters of the church. As a role model to many, I did not want to project an image of a failure, yet I had such a good reputation. I feared that if they got to know my story, I could discourage many young women who looked to me as a role model.*

Nelly was negatively impacted by her dysfunctional marriage more than I had imagined. This was evidenced by the many times she told of this experience in the course of the inquiry. The trauma of a failed first marriage was so immense that it did not heal, even though she was now married to a loving man. It was as though she seemed unable to overcome this disappointment.

> *I am trying to reconcile myself to accept that I am on my second marriage, something I did not want or had not anticipated. The idea of being in a second marriage had disturbed me for a long time. I am slowly accepting that my first marriage failed when I was young. But now, I need to accept the reality of the second marriage. It was not in my plans to have different fathers to my children.*

Although I was certain that I was not the first to hear about the failed marriage, I wondered how she told this story to others. Numerous times throughout our conversations, anytime she raised the issue of her marriage to Moses, her voice changed and quivered as she fought off tears and attempted to steady her emotions and regain her composure. To my surprise, at times Nelly laughed at herself sarcastically as she relived them. As she lived some of these stories, I often wondered if she felt as though some of the stories she lived and told, though traumatic, were awkward for her to hear. Over time, she shared how this dysfunctional marriage predisposed her to HIV infection.

> *Before getting married, I lived a good life as a Christian, certain that it is impossible to get HIV if you are married and morally upright. I thought that being married is a safe bet from getting HIV. I got married in a church to a Christian man who we got our first baby 2 years into our marriage. Soon thereafter, he became unfaithful. When I reported his unfaithfulness to the church, I was encouraged to forgive and forget, move on because it may as well have been a mistake. I really trusted him so much, and I felt betrayed that as soon as our child was born, he decided to mess with our marriage. He would come and beg for forgiveness whenever he became unfaithful. I told him that since it is risky to have extramarital affairs, it is good for us to know our HIV status as we are in the era of HIV.*

When Nelly was committing herself in marriage, a dysfunctional marriage and a fear of HIV infection was the last thing on her mind. I imagined her standing in front of a clergyman, in a white bridal gown with a flower bouquet on her hand, receiving a wedding ring from Moses as he made vows to her. Did these words make sense to him? I wondered. What did they mean to him?

I Moses take Nelly, to be my lawfully wedded wife
To have and to hold, from this day forward
For better for worse, for riches for poor
In sickness and in health
To love and to cherish
Till death do us part
According to God's holy law
And this is my sovereign vow
(Marriage vows)

Nelly grew up as a committed Christian woman whose expectations were that she would be married to an equally committed man. Having a church wedding, in the presence of many witnesses, where she vowed to her husband by saying *I do,* underlined her deepest commitment to him. Being a Christian, her values were informed by its teaching and she storied herself as a trusting partner who also expected the partner to be trustworthy. Her physical and emotional security was based on shared values, beliefs, and practices.

Therefore, it was natural for her to assume that in marrying Moses, he would abide by the shared values. However, during the second year of their marriage she noticed that Moses changed and became unfaithful to her on numerous occasions. Nelly had never fully understood what precipitated Moses to be unfaithful to her, and only got wind of it after the birth of their first child. I wondered if Nelly knew Moses well before she married him. In protest, Nelly occasionally separated from him, but forgave him whenever he came back. Nelly's persistence in this dysfunctional marriage was sustained by social influences that persuaded her believe that forgiveness was the only antidote to Moses' unfaithfulness.

> *My parents would exhort me to forgive and move on and I would go back to him. I also felt pressured to cling on to him since he was my first love.*

With every report or rumor of Moses' unfaithfulness, Nelly knew that HIV infection was a possibility. When she became pregnant for the second time, she needed to know her HIV status in order to protect her unborn baby, and also take charge of her own destiny. As she told this story, in a matter-of-fact-tone, I wondered how her life would change based on the outcome of the HIV test. Would it cause Moses to change?

> *When I became expectant with my second born, I reasoned that I needed to know my status so that I could protect my unborn baby should I be infected with HIV. I implored my husband to go with me for the test but he flatly refused. At the end of the month, I asked him for Kenyan Shillings 500 (CAD 7) and I secretly went for the test. That was in 2002. When the test came back positive, my body weakened due to the stress I was under. I was in denial because I never thought it could happen to me, a Christian woman married to a Christian man. I was so disturbed, but managed to bring the results to my husband who dismissed it as fake. This denial tormented me even the more; I asked him*

> *to go for the test together with my first-born child. The first-born was HIV negative, but my husband refused to take a test. I thought he would be remorseful and change after counseling. With time, my husband's behavior worsened; friends and church gave up on us when he did not change.*

Nelly's individual agency in charting her own path was evidenced by her decision to go for an HIV test. Although a positive HIV test caused her great indignation, the lack of remorse on the part of Moses further tormented her. Nelly believed that Moses was the 'cause' of her HIV infection. In the meantime, Nelly shouldered the HIV burden alone, seething with a sense of injustice and victimization by a disease that did not distinguish between the faithful and unfaithful. As an innocent victim, she agonized to come to terms with the fact that she had become HIV positive. Furthermore, having constructed an identity of a faithful Christian woman, accepting an HIV identity was hard to do as she deemed it incompatible to her faith. How would her friends perceive her if they learned she was infected with HIV?

Although it had been 11 years since she was diagnosed with HIV, Nelly was still tormented by the fact that her partner's infidelity was responsible for her HIV infection. Sitting opposite her, I realized that I was neither prepared for some of the narratives she shared, nor did I have had an appropriate response to them. I wondered if Nelly's intense anger at Moses was transferrable to me. In the heat of her anger, I wondered if I had a duty to respond to her in any way. As she agonized over the painful memories of a failed marriage and an HIV infection, it was clear in her mind where the responsibility of this "calamity" fell. Her bitterness was so venomous that it irreparably destroyed her trust in men and the institution of marriage. All I could do in that moment was to hold my chin and momentarily avoid eye contact with her. In my imagination, I could see Moses' cruelty to Nelly as his unfaithfulness went unchallenged. Did he realize what he was doing to Nelly? Yet I wondered if there was another face to this story? What would Moses' version of the marriage experience look like? I nonetheless restrained myself from getting carried away with my imagination.

The illusion that HIV infects only sexually promiscuous people hindered Nelly's acceptance of her own HIV status. Yet, Nelly's experience illustrated women's helplessness to protect themselves against HIV infection even when they were aware of the risks involved. Furthermore, the fear that her marriage would be deemed a failure combined with her financial dependence on Moses, may have prevented Nelly from separating from him as soon as she became aware of a change in Moses' behavior. In addition, the loss of her two parents in quick succession further weakened her support base. She subsequently became disillusioned and overwhelmed to the point of contemplating suicide.

> *I made up my mind thereafter that our marriage was not working for us. Before delivering our second child, I contemplated suicide, to save myself from my troubles. I planned to throw myself in a sewer along with my son. On the day I was to execute my suicidal plans, I was distracted by a friend who invited me to her home and encouraged me to persevere even though she did not know what I had planned to do. Later on, I left for home and dropped my suicidal plans, determined to give a hope and future to the fetus I was carrying and my baby.*

Although committing suicide is stigmatized in many communities, the fact that Nelly had contemplated it was an indicator of how overwhelmed she felt in dealing with her HIV infection, a failing marriage, and the lack of social support. Nelly was forever grateful to the friend who unknowingly intercepted and halted her suicidal plans. This interception became a turning point in her life; she rededicated herself to protecting the future of her born and unborn children. She subsequently decided that her marriage was irreparably damaged and took steps to dissolve it.

> *I decided to move out of the matrimonial home and live for my children. I rented a small house in the neighborhood and began a new life as a single mother. I did menial jobs such as doing laundry work to support us. Even then, my husband followed me and became physically and verbally abusive. I could not fight back because I could see he wanted us destroyed and I did not have ways to counter his aggressions. I began to avoid him and asked him to leave us alone and be a good neighbor. I implored him to move on with his life. Out of these menial jobs, I saved some money and began a small business.*

Unemployed, pregnant, and a mother of one, Nelly knew that disconnecting herself from her only source of financial sustenance was a risky move. Due to her financial limitations, Nelly could only relocate a short distance from her former home. A break from this toxic relationship nevertheless, allowed her to thrive physically, emotionally, and financially.

> *Without the marital stress, my immunity and strength picked up. My business flourished and I was happy that I had moved on. I had faith in God that he will take me through. I constantly prayed to God to give me resources to provide for my children. I then enrolled for HIV support group.*

Nelly's newfound freedom was short-lived as Moses continued to destabilize her. Unannounced, he took their two children from her, leaving her tormented, heartbroken, and lonely. Although Nelly was not sure how long the children would be gone, she continued to receive reports of child neglect, malnourishment, stress, mental torture, and anguish. As a mother, her children's suffering was too much to bear. In reliving the pain she experienced, she cried inconsolably, wetting all the napkins she had. As I sat next to her, I could only nod in acknowledgement, unable to fully grasp the pain she experienced. After regaining her composure, Nelly told me that although these experiences were destructive and disruptive, they deepened her understanding of the magnitude of the mental, physical, and emotional agony children at times experience in difficult marriages. Subsequently, through these experiences she was able to empathize with children and their HIV positive parents who sought her assistance.

> *Working at the Children's section of Utumishi, I am aware that children living with HIV have personal issues and whose behavior is greatly affected by the environment they live and operate.*

Somehow, Nelly regained custody of her children. After a couple of years of separation, Nelly decided to give marriage a second chance. This was after Moses approached her and convinced her that he had changed. However, this reunion almost ended calamitously, when Moses attempted to murder her.

> *After being separated for a couple of years, Moses pretended to have reformed, and so I let him into my house. After a couple of months living together, he attempted to kill me. On this particular morning, after I took my children to school, he closed the door and strangled me. He wanted to do it in such a way that it would look like robbery with violence. As long I was alive, I was an obstacle to his attempt to marry whomever he wanted.*

The attempted murder by Moses was a wakeup call to Nelly in many ways. Although she felt naïve for having believed that Moses had changed, it provoked a reevaluation of her life. At that point, her personal security was of paramount importance. She no longer felt safe as long as she lived in the same town as Moses. She told me that after reporting the matter to the police, she was advised to hire guards to watch over her at night. This was an unrealistic suggestion given her financial situation. Moreover, her issue was dismissed as a domestic one, with the police showing little interest. Meanwhile, her siblings relocated to Ukweli so that they could be with her. Nelly knew that she needed a long-term solution to address her insecurity. While she struggled to accept the idea that her marriage was effectively over, remarrying was a challenge but yet a necessity, at least to ensure her security.

> *After the attempted murder, I began contemplated getting into a relationship with a single man who was also HIV positive. I did not want to break someone's marriage. I thought it was time to look for a man who will understand me and my life. My brothers encouraged me to remarry so that I would be protected against my ex-husband's*

> *aggression. It took a while for me to reconsider remarrying; meanwhile I successfully dissolved our first marriage even though he was uncooperative.*

Unlike in her first marriage where she waited for Moses to propose to her, when Nelly decided to remarry, she actively took charge of searching for and identifying a potential spouse who exhibited particular qualities. Besides looking for a companion, she also needed someone who would protect her from any future aggression from Moses. Therefore, when she met George, a 6'1 tall, 220-pound man, she knew that he had the right credentials to be her shield and defender. Although companionship and intimacy was secondary compared to her security, in George she found a respectful, nonviolent, faithful, and supportive person. Although Nelly was not forthcoming where and how they met, she told me that sheer coincidence played a big part in their first meeting. In no time, Nelly and George realized that they had many things in common. These included shared faith and beliefs, a traumatic past, and HIV infection.

> *I met him (George) in town, and as we shared, I learned that he was HIV positive. I had chosen to disclose my status before the relationship went far. He was also on antiretroviral medications. I also learned that he had similar experiences to mine that I will not share today. He seems to have been heartbroken by the previous relationship. Since I had done an official wedding in my first marriage, we decided not to make our marriage official. I was still skeptical of men, even as I entered this relationship. Once beaten, twice shy. We began to learn from one another and I later came to learn that he too was also a Christian. He accepted my children and now we have a daughter together.*

Nelly shared very positive things about George, whom she described as the exact opposite of Moses. Her face radiated with joy whenever she talked about how respectful, supportive, and loving George was. Furthermore, he had embraced her children as his, and they had since had a child together. As she told how her life changed after marrying George, I could not wait to visit them and get a collective narrative of how they were building their lives together. We planned a visit one Sunday afternoon, when Nelly was certain that George was available.

I arrived at Nelly's neighborhood at 4:00 p.m. and found her waiting for me by the roadside. I parked the car next to their house, a rented two-roomed permanent house adjacent to others in a long row. Nelly welcomed me to their house and I was made comfortable on one of the sofas near the door. Across from me sat George, holding little Anastasia who was slightly over 2 years old. She held tightly onto her father's shirt, feeling a little insecure by my intrusion. When Nelly left for the kitchen to make tea, I wondered how to engage George as I was not sure what Nelly had told him about the visit or me. Who was I to her and them; a researcher, a visitor, or a friend? However I was labeled, I knew there were bound to be some expectations of sorts and not knowing them, I struggled to initiate a conversation with George. "Exactly what do you do?" were the words that broke the 2-minute silence between George and me. "I am a Kenyan schooling in Canada," I said. "I am here to collect data for my PhD," I continued.

The mention of the name Canada was the icebreaker we needed, becoming a common denominator through which our conversation was based. In an instant, George told me about his sister who lived in Toronto and wondered if I lived in Toronto. From my cell phone, I showed him the Canadian map and traced Toronto and Edmonton. That way, he was able to visualize the distance between the two cities. For the 20 minutes Nelly was in the kitchen, George did most of the talking about his childhood, schooling, and struggle with poverty, and how he eventually settled in Ukweli. I was careful not to mention HIV in my conversation and given that George did not know I knew his HIV status, it was safest if he led the conversation.

George connected well with his daughter Anastasia. Since the time I got to the house, she sat on his lap and rarely moved, enjoying the comfort and protection of her father. When Nelly finally emerged from the kitchen with a kettle of tea, he created space for her on the sofa and she sat next to him. Nelly graciously served her husband tea and from their body language, they were comfortable in each other’s company. It had been 3 years since they had married. The two appeared well settled in marriage; George had even begun planning to build a family house on a property Nelly owned. Although George was financially unstable at the moment, he played a vital role in stabilizing Nelly’s life. Since their marriage, Nelly had enjoyed stability and safety.

In the midst of the conversation with Nelly and George, my mind reflected on the stories Nelly had shared about living with Moses her first husband. Although Nelly was physically joyful in the presence of George, I wondered if he matched the qualities of a husband Nelly had always desired. How different was George from Moses? How did George see himself in the marriage? I wondered. We spent about 2 hours visiting together and as I left the house, I was impressed that although they lived in a humble neighborhood, there was joy, happiness, and mutual respect between these two who clearly loved one another.

With a stable marriage and three children, Nelly had the impetus she needed to build a stable future. Both Nelly and George dutifully took antiretroviral medications and supported each other to live positively with HIV. Both Nelly and George had a common vision and purpose in life, something Nelly had lacked in her previous marriage. This purpose and stability was demonstrated when Nelly enrolled in high school to complete the schooling she missed. She graduated and embarked on a counselling course, which, according to her, would make her more effective in the work she did.

> *I used to go to school 1 hour every day, and covered the secondary syllabus in 4 years. I sat the national exams in 2011. Since then, I have attended many counseling and HIV related short courses while working at Utumishi. Now I am taking a certificate in counseling. I have taken trauma counseling as well and I have immense experience in counseling.*

Although embracing an HIV identity is a work in progress, the HIV support group at Utumishi was an immense help to Nelly to accept herself and her situation. Nelly began attending support group meetings as soon as she was diagnosed with HIV. Becoming part of a network of PHAs who came together to share personal experiences, emboldened Nelly to share her experiences as well.

> *When I gave birth to my second born son, I met young women like myself coming for support group meetings. I was greatly consoled seeing that I was not alone in this struggle. I was surprised to see how people disclosed with ease. In the group, there were all manner of people including school going children. My confidence to deal with my disease grew and I was determined to live positively with HIV illness.*

By attending the support group meetings, Nelly's spirituality was greatly enhanced. It was here that she was introduced to a recitation called *Serenity Prayer*, which exhorts PHAs to pursue personal acceptance for the things that are beyond their control, such as HIV infection.

> *When I began to attend the support group, we used to pray like this* ***"God grant us the serenity to accept the things we cannot change, courage to change the things we can, and the wisdom to know the difference."*** *So I accepted that I cannot change my HIV status, although I had faith, the virus was not getting out of my blood. I chose to accept it. I began to live positively and did not look like someone who had HIV.*

Nelly told me that the serenity prayer was the anthem that members in the support group chant before, during, and after the support group meetings. Whenever they collectively did so, they felt inspired and invigorated to live positively as PHAs. Although she had never known the source of this prayer, Nelly singled out this prayer as key to her accepting her HIV status, overcoming HIV stigma, and her social situation. In the following text, she clarified what this prayer had meant to her over time.

> **I cannot change:**
> My HIV infection,
> My failed marriage,
> My second marriage,
> My loss of parents,
>
> **I can change**
> My attitude towards my disease,
> My bitterness towards my ex-husband,
> My attitude towards others with HIV,
>
> **I now know the difference**
> That forgiveness is a choice,
> Acceptance is a choice,
> Positive attitude is a choice,
> Looking forward into the future is a choice,

In the dialogue below, she further amplified what this serenity prayer meant to her.

R: We were given this prayer when we enrolled in the psychosocial group for the first time.
I: Do you know where it came from[23]?
R: Actually, I do not know its origin, but the facilitator of the support group meeting helped us understand what it means. God grants us the serenity to accept the things we cannot change. I was in Western Kenya, now I am in Ukweli, my parents are no longer alive, I am no longer a youth, I am married, but unfortunately things fell apart. Let me accept my situation and live the way I am. Another thing, I was in Western Kenya an HIV negative person, but now I am in Ukweli as an HIV positive person. I could not change these things. Being HIV positive, being in a new marriage are the things I cannot change. Then there are things I can change. I almost gave up on life, but I have a choice and power to change from despair to hope and determination. I turned around and promised myself to move on. I was able to cope with the support of the colleagues who helped me accept my status and situation. I also had to change my relationship. I could not mourn forever about my broken first marriage. I had to make a choice and enter into a new relationship and be in a relationship with the other partner whom I am married to.
I: So you try to live that prayer?

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[23] I looked to the internet to learn the source of this prayer, and it was apparent that it is a popular one. However, I was unable to trace who authored it.

R: Of course and the wisdom to know the difference. Like for instance, when we were hired, we were employed because we were living with HIV. If I was not living with HIV, I am sure I would not have gotten this job because I had a different career.

In the course of time, we also met for lunches and held informal conversations. Strikingly, Nelly always revisited experiences of her failed marriage and how it changed her life. I often wondered why she struggled to overcome these experiences which evidently retraumatised her whenever she lived and told them. Reflecting on the stories she told me and the experiences she shared, it became apparent to me that her life and her experiences of living with HIV were more intriguing and complex than I had first imagined. No matter how positive she seemed as an HIV lay worker, counselling HIV clients on the need to be hopeful and to disclose their status to others, privately, her past haunted her. To me, she remained in a state of mourning over the loss of her innocence, and a sense of injustice and victimisation by a virus that did not discriminate between the faithful and unfaithful. Although she was happy to be married again to a husband that appreciated and loved her, she mourned the loss of her first marriage and struggled to reconcile the fact that she was in her second marriage.

My last lunch conversation with Nelly occurred immediately following the visit to her home. I thanked her for all the stories and the times she had shared with me. She told me that her husband was happy that I visited with them and that he was expecting my call. Although he had given me his cell phone number, I did not know if there was any expectation on my part to continue a relationship with him, since he was not my participant. Through attending to Nelly's experiences, I recognized how complex the impact of the psychological trauma of HIV infection was to her. Furthermore, by attending to her experiences she lived and told, her personal struggle to deal with the social effects of HIV infection became apparent. I wondered what Nelly needed to do in order to give closure to those experiences that kept coming back to haunt her.

Chapter 7: Narrative Account for Luanda

Lunda was the only potential participant that John felt was very enthusiastic to be involved in my study and whom he also called a loyal servant of Utumishi. This compliment made me eager to get to know Luanda and inquire into his experiences. I wondered why John described Luanda in the way he did. At my earliest opportunity, after getting Luanda's phone details, I called him to set up an appointment. Luanda sounded enthusiastic to receive my call, telling me that he was "thoroughly" briefed about the project by John and that it would be an honor to be involved in this study. He invited me to meet him at a green and white striped tent within the Utumishi complex, where his workstation was located. Within a couple of minutes, I was standing at the entrance to the tent. Inside the tent, two small plastic tables were joined together and two chairs were set facing each other. It looked as though I had entered a counselling session. Luanda welcomed me and after a brief exchange, asked me to wait on one of the chairs as he finished his interactions with a client.

Luanda received me with courtesy, expressing great delight that he had finally met me, having heard about me from John. Since he was fluent in English, he read the information letter and the consent form without asking any questions. He came across as a warm and engaging person who freely volunteered any information I asked for and went out of his way to clarify, explain, or offer details over and above what was asked. He was so generous with the information he offered that following the 10 minutes I spent briefing him about the research I felt as though I had come to know him extensively. However, given that I had not carried a tape recorder on this day, I hoped he would retell his experiences in the coming days and months.

Signing the consent form for the research turned out to be a mere formality, since Luanda had made up his mind even before I approached him to participate in the study.

We agreed to meet again 4 days later at the same tent and as I left the tent, I met a small group of clients seeking his attention. I later learned that a majority of them had missed their scheduled HIV clinical appointment at Utumishi, and had come to Luanda to facilitate a rebooking of the appointment. In this role, Luanda got to know the clients' stories and experiences and because of his friendly and sociable nature, he made friendships with them with ease. Many clients therefore come back to socialize with him, while others called him on his cell phone seeking advice or greeting him.

Exactly 4 days later, I arrived at 9:00 am for our first research conversation. During this part of the day, he saw fewer clients. Pulling two chairs from the closest row, we sat facing each other. I turned my voice recorder to record every word that Luanda shared with me. He told me that he had just finished facilitating an HIV peer support meeting for discordant couples and that he had other support group meetings lined up for later in the day.

His statement "*I was diagnosed with HIV in 2002, and I had to undergo a lot to reach the level that I am"* set the stage for a rich conversation during which Luanda shared details about his life in general, learning about his HIV status, his marital issues, working for Utumishi, and living his HIV identity in particular. Prior to receiving his HIV diagnosis, Luanda storied himself as a career tours and travel guide and a businessman in the transportation industry, living a life of affluence and pleasure. He had everything that a family needed to live a comfortable and middle class life. His work in the tourism industry as a tour and travel agent often took him away from his family, spending long periods in the coastal cities and other tourist attraction sites such as national parks. He did not deny himself anything that would give him pleasure.

> *R: I was a sales agent of a five star hotel in a coastal city and tourists booked their stay through us. We would lead a tourist convoy from a mainland city to a coastal city to these five star hotels, to pursue a life of indulgence, sex, drugs, and partying. The tourists too wanted to savor the nightlife and whenever I would take them to coast, I would find myself indulging in risky behaviors.*
> ***I: In relation to HIV, so you think the coastal city offered more women, sex?***
> *R: In this coastal city, women had money. You could easily become a victim, thinking that you are being entertained . . . So you find that due to humid weather, some tourists would come with a swimming costume in a club. ... I was also taking khat, and we would spend a day in the beach chewing khat.*

In particular, Luanda singled out a coastal city that had significantly influenced his life due to its allure. This enticed him to indulge in risky sexual practices and drugs. As a family man, I wondered how he balanced his professional and occupational responsibilities with his social roles. However, his confession later in the conversation that he had been married four times made me wonder if his lifestyle was responsible for his many marriages. I sought to understand the details of these marriages as our relationship unfolded.

Luanda later told me his first two marriages ended in desertion, which was traumatic and painful for him. Margaret, Luanda’s first wife moved to a country in southern Africa without his knowledge, taking their two children along with her. Although this event happened 19 years earlier, reliving this experience opened up old wounds that reminded him of how unceremoniously his first marriage to a woman whom he referred to as his first love ended.

> *My first wife went to visit her sister in a southern African country in 1994 and never came back. Initially, I thought it was just a visit, and she was to come back after her leave was over. When her time to resume duties came and she took long to resume, I enquired from a colleague who told me that she had resigned ... I felt betrayed by her.*

Luanda had met Margaret in college when they both were students. They got married soon after and had two children. Luanda never understood what caused Margaret to desert him. He told me that he was retraumatised every time he thought about how he had blindly escorted his family to the airport, totally oblivious that his marriage was effectively over and that this would be the last time they would see each other. The only evidence of this marriage was a passport size photo of his daughter Jackeline, taken when she was 3 years old, which Luanda kept in his wallet. This photo had been with him for 19 years, passing through and between wallets and clothes, and was still presentably intact and appeared like new. Like a guardian angel, this photo had watched over him in moments of high and low, in good and bad times, and had outlived two other marriages. Although he did not know where Jackeline was, he hoped that she would one day look for her father and that they would be reunited.

Luanda never spoke much about who he was as a family person. I wondered how he balanced his career, family demands, and the social life that he led. Did Margaret know about the life of indulgence that he led? And if so, was that the reason she deserted him? Luanda remarried soon after the desertion by his first wife. Although by every account it appeared to be the right thing to do, I wondered if he had completely recovered or dealt with the trauma of the first marriage. Luanda rarely saw his second wife Angela because they were both busy with their own lives. Luanda did not bother to formalize the marriage with Angela since he had not dissolved the first one. In my mind, as he retold this story, it was apparent that this marriage too would end in disaster based on mistrust and a lack of communication that was magnified by their busy lives. I wondered about Luanda's philosophy of marriage and what he saw his role to be within the marriage.

Marital disharmony between Luanda and Angela became evident during the delivery of their baby Nina. Luanda told me that he was expecting to be involved in delivery plans but to his surprise, he was not involved in the delivery of his baby. Instead, his wife moved upcountry to deliver their child there. Angela left the baby upcountry in the care of her mother; Luanda never got a chance to hold or see her. Although Luanda was understandably angry by the way Angela treated him, he nonetheless felt helpless to make any demands since he had not formally married her. Looking at this event now, Luanda wondered if there was anything Angela was hiding from him by behaving in this manner. Was she acting in a manner to suggest that she did not recognize Luanda as her husband? He would never know.

> *I remarried in 1997 and my wife became pregnant almost immediately. When her time of birth came, she went to her rural home to deliver from there, leaving good hospitals here in the city. We were staying in the city at that time. I did not understand why she chose to do that and more still, she left the baby with her mother and came back to the city alone. Reflecting back now, I wonder if she knew that she had HIV from the antenatal clinic and was trying to cover up, by going to deliver away and leaving the child behind so that she does not raise suspicion by not breastfeeding. I do not know what she was hiding. It was unusual to deliver at home, and leave the city where there are good hospitals, and worse leave the baby in the village.*

If Luanda was shocked by Angela's conduct, the events that followed were even more bizarre. Recounting this experience moved him to tears, making him speechless. Luanda, normally an eloquent, oratorical man, who was fluent in English, lost his breath, paused, bit his lip, gazed at the horizon and shook his head as though in disbelief that it could have happened to him. Luanda was visibly bitter when he recalled how he was mistreated by the people he loved most at the weakest moment of his life. Before telling about this experience, Luanda had cut an image of a composed, collected, and confident man. The sight of a man wiping tears from his eyes was overwhelming to behold, breaking every cultural stereotype that depicts a man as emotionless and tough. Was he at his most vulnerable place with this telling? Although he could not recall all the details of the sickness, he knew he had suffered from a serious illness that would later become a turning point in his life.

Luanda recounted that he became so gravely ill that everyone in the family thought he would die. Subsequently, they moved him to a "poorly equipped hospital" near his rural home to die there, a cost saving move or so he thought. The fact that financial consideration dictated the choice of care he received and knowing that his family had given up on him living, evoked a bitterness that refused to subside.

> *I fell ill in the city, soon after my wife delivered. The sickness affected my memory and I became mentally ill. People tell me that I was behaving weirdly. My family feared I might die in the city, so they brought me here in Ukweli, perhaps to die near home. I was admitted here right away. My sister is based here in Ukweli and she had offered to take care of me, as I had deteriorated so much. I also think they might have suspected that I was dying and so brought me closer home. I still do not understand why they took me away from the city, where there are better hospitals than Ukweli. When I was moved to Ukweli, my wife was left in the city, and she used to travel a lot. She never came to see me and did not care about my welfare. I wonder if she thought I would die. We kind of separated. So it was not a stable marriage. I was discharged a week later to go home. The doctor told me that according to my condition, I would be going to room A, where the HIV clinic was based.*

Later on, Luanda told me that he was diagnosed with meningitis and the attending doctor tested him for HIV without his knowledge. During his discharge teaching, in the presence of his relatives, the doctor told him that he was HIV positive and would therefore be discharged through the HIV clinic. Since Luanda was too ill to give a consent for an HIV test, he wondered where the doctor had obtained this consent. Did he even seek one? Luanda would never know. But to have a health practitioner test for HIV without consent and communicate the results in that manner was unforgivably painful. His wife Angela never visited him while in the hospital and instead, opted to move out of their shared residence as soon as his admission to the hospital was confirmed.

In attending to Luanda's telling, I understood why he was entertaining conspiracy theories about how and why his sickness was handled in that manner. After his family gave up on him living, his wife deserting him, and his attending doctor's unethical practice, Luanda had no one to advocate for him. Unethical as it was, I was not entirely surprised that Luanda was tested for HIV without his consent. I remembered my experience working in a medical unit as a Registered Nurse, when any patient who presented with opportunistic infections such as meningitis, tuberculosis, or persistent diarrhea was automatically suspected to be infected with HIV. Often times the practitioners did not bother to inform or counsel the client before undertaking this test as the client was often too ill to consent. At the time, HIV counselling protocols were either nonexistent or rudimentary and the prerogative to test for HIV fell entirely on a practitioner. Numerous times, I witnessed medical students draw blood without patients' consent to test for HIV. And even when HIV test results were positive, patients were not always told. The results would be filed in the patient's chart, accessible for anyone with roving eyes to see. Coded language such as ISS (immunosuppression) to mean HIV were often used to refer to HIV positive clients who were often clustered in a small cubicle at the farthest end of the unit. I wondered if this was what Luanda experienced.

> *I was not counseled and I suspect that they may have tested for HIV without telling me. I was being treated for meningitis. I remember they did lumbar puncture, drew cerebrospinal fluid from my spinal cord. The moment they mentioned that I was infected with HIV, I do not remember anything else. I was so confused at that time. I do not remember if my sister was there …. However, when I was discharged in 2002, I wanted to die; I was not ready to live with HIV.*

Luanda would never know the considerations that led his family to have him admitted in a poorly equipped hospital in a rural town. However, imagining someone dead or giving up on someone living is a taboo in many cultures in Kenya. Furthermore, Luanda was pained to learn that the people who ought to fight for his life, somehow had given up on him. Furthermore, his sister Mercy was so confident that Luanda was dying that she misappropriated 160,000 Kenyan Shillings (CAD 2000) that he had entrusted to her, confident that he would not live to claim it. She was surprised, just like many of his relatives, that he did not die and that he needed his money back. Her relationship with her brother Luanda declined irreparably due to her greed.

> *When my sister learned that I was almost dying, she began to disinherit me of my property. She refused to give me 160,000 Kenyan Shillings (CAD 2000) I had loaned her. I sought the assistance of the legal office here at Utumishi to recover my money. Now she pays me 5000 Kenyan Shillings (CAD 65) every month through our legal office. Due to this, our relationship soured irreparably.*

Discharge from the hospital plunged Luanda into a world of uncertainty. Luanda had no one to call family as Angela had left him, and his relationship with his relatives was broken. Luanda never understood why Angela never visited him in the hospital or where she had gone. He confided that he was too embarrassed to look for her, given that he bore physical manifestations of HIV infection. I wondered if Luanda had mistaken Angela for a spouse. Did she see herself as a friend of convenience? Why did she not stick with him when he needed her most? Had he suddenly become a liability to her? These many questions were in my mind when I thought about how quickly his two marriages ended over a span of 4 years.

> *I lost touch with my wife after the discharge. I was even avoiding her. There was a big change in my body and it was obvious that anyone would notice I was infected with HIV.*

HIV diagnosis triggered Luanda to the self-realization of his bodily changes that betrayed his HIV status. Furthermore, he still felt aggrieved by how he was treated in the hospital, feeling as through he had been robbed of all his dignity. Moreover, he was still recovering from meningitis and perhaps other opportunistic infections. Self-isolation as a way to self-preservation became a plausible short-term solution to the social and psychological trauma he was experiencing. Although he enrolled at an HIV clinic for follow-up, Lunda needed more than medications in order to begin a new life. In the absence of any social support, he slipped into depression and alcoholism, making adherence to the HIV regiment impossible. Alcohol became his closest friend and a companion whose soothing effect temporarily numbed the pain he was experiencing.

> *I was not ready to live with HIV. I resorted to drinking lots, although I was a moderate drinker. I could down half of vodka before taking beer. I went back to my rural home, but would occasionally travel to the city. I realized that I had lost lots of weight due to the illness. I fell sick and was readmitted to a hospital.*

Luanda told me that as soon as he was diagnosed with HIV, he lost the drive and desire to work and never returned to his previous job as a travel consultant. He also neglected his transport business, which collapsed soon after his HIV diagnosis. This signaled the beginning of his financial decline:

> *Being infected with HIV weighed me heavily because I am the breadwinner in the family. I am third born in our family and everyone depended on me for support. I am the most educated of all the siblings and I assumed responsibility for our family. By being infected with HIV, I felt unable to carry out the role I was playing before. My mum was going to die if she knew I was infected with HIV. So, I drunk to mask the pain I was going through.*

With no social support and a reliable income, Luanda relocated to his rural home to be looked after by his mother. It was there that he met and began living with his sister in-law whose husband had died of HIV a couple of months earlier. Taking advantage of the wife inheritance[24] custom, she became his third wife. Knowing that she could be infected with HIV was not a deterrent to Luanda. I wondered if he was aware that HIV reinfection with diverse HIV strains, could cause resistance to the antiretroviral medications he took. Did Luanda feel unable to live without a woman in his life? I wondered.

> *I inherited my brother's wife after he died. You know in our Luo culture, we are allowed to inherit a widowed sister-in-law. Incidentally, I was very close to her, and in all my hospital admission, she was the one who assisted me. But reflecting back, I think my brother died of HIV although at that time, I did not have enough knowledge to be certain. In total, I had three children with her until 2006 when I came to Ukweli…. I also realized that whenever I was in my rural home, I used to drink a lot but when I am in Ukweli, I never drank alcohol. So, it was healthy for me to change the environment to stop drinking.*

Sitting across from Luanda during this conversation, many thoughts crossed my mind. It would have been very easy for a non-Luo person like me to judge Luanda, for the choices he made in life, especially those related with wife inheritance, a practice that that has been a major driver of the HIV pandemic in Luo Nyanza[25]. To be inherited, a widow is required to engage in sexual relations with a male relative or clan member, soon after the burial of her husband. As a cleansing ceremony, it ensures that no bad 'omen' would befall the family of the deceased. As a century old tradition, wife inheritance was designed to protect the vulnerable orphans and widows. Over time, wife inheritance has become a tool of sexual exploitation and oppression. Although that may not have been the case with Luanda, he may have felt an obligation to fulfil this cultural obligation towards his sister-in-law.

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[24] In the Luo culture, if a woman is widowed, she must have sex with a man to "cleanse" her. Often, the man is a relative, a village elder, or a friend. This practice is called wife inheritance and has been blamed for HIV spread in Nyanza region which has an HIV prevalence of 15% compared to a national prevalence of 6.2%.

[25] Luo Nyanza is a region in western Kenya.

Soon after, Luanda developed liver complications and resistance to antiretroviral medications due to his alcoholism, which had negatively compounded his adherence to antiretroviral medications.

> *I developed resistance to first line of treatment, and at the moment, I am on the second line of treatment. I would lie to the doctors when they enquired why I was developing resistance to the treatment. When I was being put on the second line of treatment, I was warned that if I developed resistance to them, I would have no other remedy, and eventually I would die. I also developed complications with my liver. I was put on a drug to boost my liver.*

Although Luanda was not certain how long he had lived in his rural home, he told me that his first major turnaround happened when he was diagnosed with early stage liver failure. This happened at a time when he had also developed resistance to a first line of antiretroviral medication. Afraid to admit his lifestyle, he sobered up when he was told the choice of treatment was getting narrower due to his resistance to the first line of treatment. With immediate effect, he stopped drinking and relocated to Ukweli, to separate from the environment that predisposed him to risky behaviors. This relocation also signaled the end of his third marriage.

> *When my liver was failing and I was told that the second line of treatment is my last chance, I woke up. I actually had to stop drinking and accept my status. My friends wondered why I stopped drinking. I explained that due to my condition, I had to stop. So it took me about 5 years to accept my status. Once I joined the psychosocial group, it became much easier because I could talk openly about my status and the challenges I was facing.*

Luanda immediately relocated to Ukweli city, leaving behind an environment that predisposed him to risky behaviors. As soon as Luanda relocated to Ukweli, his wife and former sister-in-law moved on with her life too. The determination to turn his life around paid off, which was augmented by the HIV support group meetings he attended.

> *Although I had no intention of attending support group meetings, even after much prodding from the staff at Utumishi, when I first attended the meetings, I was drawn to the personal experiences of living with HIV that the members shared. I realized that people there have moved on with their lives and were healthy looking. At some point, I doubted if they were pretending to be HIV positive so they can encourage us, due to their physical appearances.*

Luanda considered himself fortunate that he enrolled in and began attending, albeit reluctantly, HIV support group meetings that were offered by Utumishi. At these meetings, he networked with other PHAs, shared with and attended to other PHAs' experiences. Through these meetings, he learned self-acceptance, positive living, and embraced his HIV identity. Furthermore, Utumishi's financial support enabled him to start a new life in Ukweli.

> *When I was reenrolled on HIV program at Utumishi, the ASO paid for my house rent for 1 month with Kenyan Shillings 700 (CAD 9). I was also given Kenyan Shillings 1000 for upkeep (CAD 13). I used to do menial jobs so that I could sustain myself such as construction jobs. I earned Kenyan Shillings 200 (CAD 2.5) per day doing these jobs. I walked for long distances to go for these jobs. I did that until I got this job.*

Between relocating and getting a job at Utumishi as an HIV lay worker, Luanda depended on menial jobs and handouts from friends to survive. Recalling that a couple of years previously, Luanda was a successful career person and a businessman, his financial demise was evident. I wondered if he thought the HIV infection was responsible for his financial decline. To his credit, through persistence, willingness to learn, live, and tell his HIV story in the support group, in 2009 he was hired as an HIV lay worker by Utumishi. This job provided him with an opportunity to not only earn a regular income, but also to have a sense of belonging.

> Luanda was hired not because of his credentials, but for living with HIV and his willingness to disclose his HIV status. This has been the case for many PHAs I have met who are working as psychosocial workers, researchers, or peer counsellors. On the surface, it may appear that GIPA principles are at work here. Given that Luanda was an educated man, in the job market, he would be fetching at least Kenyan Shillings 60,000 (CAD 800) a month. As I learned later, he takes home

> Kenyan Shillings 26,000(CAD 325) per month. I am not sure if this salary is commensurate with his qualifications.
>
> Luanda, with all his diplomas gets remunerated the same as other HIV lay workers who did not even finish high school. The idea that living with a condition could be a consideration to be hired and an equivalent to or a substitute of a formal academic credentials, stayed with me. I wondered how a PHA worker is promoted or appraised (Field notes).

From Luanda's telling, I began to understand why Utumishi mattered to him so much. He felt indebted because it had saved his life. To work for Utumishi allowed him to not only show commitment and loyalty to the ASO, but also to give back to society. He delighted in advocating for the clients who were disadvantaged or who needed additional help. At Utumishi, he was so popular with HIV clients that they kept coming back to him for support and advice; others sought him out over the phone.

> *At the tent, we help sort out the members or PHAs who have missed the clinical appointments, to reschedule their appointments. Clinicians do not always understand why PHAs may miss appointment. When they are referred to this tent, I am able to empathetically assist them, because I know some may be struggling with disclosure issues and as such, they do not reveal to their partners where they are going. So, whenever they need to come to clinic, some have to sneak secretly. Others have financial difficulties and are unable to raise bus fare. The clinicians do not understand these dynamics.*
> *In addition, when one is newly diagnosed with HIV, one may feel useless, helpless, and hopeless, and may lack the drive to follow through with an appointment.*

Luanda utilized his experience of living with HIV to advocate for PHAs who struggled to keep clinical appointments. As he attended to their experiences, he was able to relate to their struggles as someone who had also struggled to adhere to care. Luanda also understood the cost of non-adherence from the perspective of a PHA. Because he understood the struggles PHAs went through, he was able to speak to their issues in forums such as support group meetings. Over time, he grew to become an expert HIV educator and a support group facilitator.

> *We have sessions for those who have accepted their HIV status and those who have not; those on antiretroviral medications and those who are not. Therefore, when I share my experience, I tell them that it took me so many years to accept myself and I am on second line of treatment. Had I joined the psychosocial group early, I would not have gone to the second line of treatment because it is expensive to the program as well. I know if the second line fails, I am done. They really appreciate these sharing. We have different sessions for singles, whose main question is "how can I get a partner, now that I am HIV positive?" I share with them how I got my partner and how accepting my situation has helped me. They get encouraged and move on.*

Spending the day with Luanda in the tent helped me to appreciate his intensity, devotion, and commitment to the HIV clients at Utumishi. He carried two cell phones to ensure that clients could reach him at any time and with ease. Furthermore, he encouraged clients to call him if and when they needed to talk to him. Every so often, Luanda received calls from the many clients who he had assisted before, asking for his advice or counsel. Throughout the day clients streamed into his tent. Some had missed clinical appointments while others sought financial and material support. I had no doubt in my mind, based on the number of PHAs who wanted to speak with him that he was popular among HIV clients.

Luanda told me that he spent most of his time away from his family. At the time, I did not understand why he preferred work to staying at home and being with his family. With time, I recognized that Luanda took great pleasure in being recognized and appreciated by the clients, which was a morale and esteem-boosting endeavor. A sense of being wanted and valued was perhaps the single most important driver for his work ethic. With all the efforts Luanda put towards work, I wondered if Utumishi paid any attention. Was that the reason John referred to him as the servant of Utumishi? Clients had a way of trusting him with their stories and their lives, and he did not bother to create boundaries in the relationships he developed with them.

Luanda believed that clients had a right to access him when they had genuine concerns that demanded instant attention at any time of the day.

> *The work we do involves dealing with male and female clients. A female client might call me after hours. I normally say help extends past office hours. Sometimes, my wife does not understand why I receive calls from clients during the off hours. I am committed to my work; I wake up early to be in office at 7 am. To me working here at Utumishi is like a calling, because what I underwent before I stabilized, I would not want anyone to go through that. I am too committed to my job.*

To put work ahead of his family is an issue that made me a bit uncomfortable. I wondered how much value he attached to family relations. Could the lack of attention and investment in family be the reason why his marriages have failed in the past? I wondered. To my surprise, it was within Utumishi that he met Anita, his current wife, who at the time was a client at an HIV clinic. The offer for lunch with Anita turned out to be the beginning of their relationship. They began living as husband and wife on the same day. It had been 3 years since they found one another, and they have a 2-year-old girl together.

> *I met my current wife when I was working at a HIV clinic at Utumishi. Her initial impression when I met her was that she was sociable. Initially, she told me she was a university graduate, although I later learned that it was not correct, as she was a form two dropout. I came to learn most of the details of her life after we had advanced in our relationship. There were other inconsistencies in her life that I figured out after doing many investigations. She told me many lies about her life, and I unraveled them with time as we continued to live together. For instance, she had lied to me about her real name, tribe, and where she comes from. I bumped into some of her legal documents and photocopied them without her knowledge. I was not deterred by these inconsistencies, as I was more curious to know who she was. I had thought that she was hesitant to disclose her true self because we were strangers. Now that we were getting serious in our relationship, I expected things to change. I was also beginning to be actively involved in her wellbeing. For instance, I needed some of her legal and academic documents to assist her in securing a gainful employment. The more I tried to get involved in her life, the more I bumped into more inconsistencies and she was increasingly becoming uncooperative.*

> How Luanda met and began living with his wife was interesting to attend to. I was intrigued how a lunch invitation turned out to be an invitation to live as a husband and wife. Did he extend an invitation to her after lunch to go home with her? Why did he not take sufficient time to know her before she became his wife? Was he under any pressure to marry? Luanda’s use of strong descriptors to describe his relationship and perception of his wife’s manner was unsettling too. I struggled to attend to him as he used strong and negative words to describe his spouse. Yet, I was not able to turn away from this conversation. In a research engagement, how could I have told Luanda that I am not keen to hear negative remarks about his wife? How was he expecting me to perceive his wife if I would make a home visit? (Field notes)

Gauging from Luanda’s opinion of his wife Anita, it was evident that he was not enthused by the marriage. Besides not wanting to spend time with her and her daughter, the scale of mistrust between them was alarming to me. He painted her as dishonest, sly, untrustworthy, unreliable, and nontransparent. While I felt uncomfortable with these descriptions, I wondered why he married her before knowing who she was. Why did it take him a day to make a wife out of her? I wondered about their future together given that he did not bother to make or address the issues that caused mistrust between them. Although Luanda seemed generous with information regarding his private and public life, I never expected him to disclose such damning information, especially in relation to his wife. Is that the reason he choose to stay at work?

After serious consideration, I visited Luanda at his home so that I could gain a sense of the family dynamics and reconcile some of the stories he shared about his life. On the day I was to visit Luanda at his home, I arrived at the place we had agreed to meet, about 7 kilometers from Ukweli town. I found him already there waiting, holding his daughter against his chest. He led me to his homestead, a 100-meter walk uphill to a newly constructed a semi-permanent house sitting on an eighth acre of land. He told me that he secured a loan to buy land and he had developed it less than 3 months ago. Luanda pulled two plastic chairs for us to sit outside the house, and we instantly became part of the village life, interacting with people and domestic animals that transected through his unfenced property.

In an instant, Luanda opened his heart to me in an unprecedented way. He began to talk about how his day began waking up at 6 am and then leaving for work by 6:30 am. Leaving work at this time gave him sufficient time to walk and be at his office by 8 am, as he could not afford bus fare. The 6 kilometer sojourn, whether in rain or in sunshine, left him exhausted by the time he reached the office. This was his daily routine since he moved into the community. To prove his financial predicament, he retrieved his paystub that showed that although his gross salary was 26,000 Kenya Shillings (CAD 330), his net income was 8000 Kenyan Shillings (CAD 100). Two thirds of Luanda's gross salary was deductions: long-term loan, emergency loan, shares to a co-operative union, income tax, and an advance on his salary. The net salary hardly paid for upkeep, bills, groceries, and any incidentals. Instead, he lived from paycheque to paycheque or on credit. Furthermore, he rarely took breakfast, and used credit to buy 20 Kenyan Shillings (CAD 0.25) worth of Githeri[26] for lunch. Since he could not afford beef for the family, he substituted it with bones and chicken offal, which he solicited from the local slaughterhouse. Each month he had a carryover debt that he had to pay with his subsequent salary. Further, as his wife was unemployed and expecting their second baby, he felt under more pressure on an already inadequate income. As he narrated his life of poverty, survival, and hope, I began to wonder how he managed to perform his duties as an HIV lay worker.

In response to the financial pressures that he faced, Luanda imagined how to improve his income situation; rearing chickens, installing a maize mill, or operating a kiosk. Acting on these

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[26] Mixture of beans and corn.

ideas made sense, but required substantial upfront capital. Luanda also hoped to pursue further studies at a local university. While Luanda could look to the future with hope and optimism, at 46 years of age, having a young family and pursuing a career, I wondered if he felt as though he was just starting his life.

> Although Luanda was married previously, the three women he had married retained the custody of their joint children. In the society he comes from, manhood is measured by the number of children he has and as such, he has no "evidence" that he was ever married before this current marriage. At 46 years, and with a 2-year-old baby, and another on the way, it felt as though he was just starting life. He seemed unable to socially and financially account for the 20 years he had worked. I wondered if Luanda has the energy to see his young children though life. Does he not fear exhaustion and burn out? (Personal reflection).

Although working as an HIV lay worker was not financially rewarding compared to his previous job, Luanda was grateful that through this job he had somewhere to call work. With massive layoffs targeting his fellow workers due to budgetary cuts, he thought that his many diplomas had somehow protected him from being laid off. Yet, because his position was contractual and renewed yearly, he was never secure in his job.

My visit at his home lasted about 2½ hours as Luanda had a speaking engagement with college students in town. On our way out, we each grabbed a boiled corn, which we ate as we walked down the road. We knew it would have been disrespectful had we gone without eating the food that Anita had prepared. I proposed that we use the route he walked to work so that I could have a sense of the effort he made to get to work. The route he used was a non-tarmacked track that cut through farms and a river, meandering around an escarpment. When it rained, it became impassable and slippery and the water could rise to the level of the bridge. In that case, his route was even longer. We enjoyed a good conversation about life in general and how Kenyan PHAs' experiences differed from Canadian PHAs. It took us about 20 minutes to get to the highway where we boarded a Matatu[27] to Ukweli town. Because Luanda was in a hurry to get to his speaking engagement, we did not walk the entire journey. However, I was able to appreciate the strenuous walking, through the hills and valleys, under unpredictable weather conditions of scathing sun and heavy rains, which he did to fulfil his work obligation. It was indeed a labor of love.

After the home visit, I proposed that we meet at a nearby restaurant for an informal conversation. As we made our orders, I reflected on the socioeconomic stories he had shared earlier on. I still marveled that Luanda would walk for 10 kilometers every day, doing without breakfast and sometimes lunch, and surviving on a shoestring budget. Living under such circumstances, I wondered how he maintained sanity to be an effective HIV lay worker at Utumishi. While I took it to be an ordinary lunch conversation, Luanda looked at it with a different appreciation. He told me that it had been long since he ate a "decent" lunch in a decent restaurant.

While I was expecting that he would be excited by an opportunity to eat out, instead, his countenance changed and all of a sudden, he appeared unhappy and disturbed, becoming a different Luanda from the one I had come to know. For the first time, he admitted to me that he was getting depressed due to the financial situation he found himself in. He also intimated that for the last couple of months, his family has been forced to make do with only one meal per day, due to hyperinflation that had led to an increase in the cost of living. As Luanda shared his

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[27] A 14 seater minivan popular for public transport.

concern, I was aware that as a contractual employee, he and others in similar employment lacked mechanisms to bargain for a salary review, since the job was not based on firm academic or professional credentials. I had many questions about how their employment terms were worked out:

> How are their outputs measured?
> How are they recognized for the work they do?
> Are they visible or invisible in the organization?
> Are they valued?
> How does their scheme of service that is based on lived experience measure up to academic credentials? (Personal reflections)

The socioeconomic strain has meant that Luanda could not afford to buy beef, which his daughter had been nagging him to provide. In his situation, surviving from paycheck to paycheck, beef was clearly a luxury. How to make his 2-year-old daughter understand his financial predicament was beyond his imagination. From this conversation, it was obvious that Luanda's ego as a parent and a provider had been bruised by forces beyond his control. I believed in the legitimacy of these concerns, given that I was privy to his financial and social circumstances. Although I was used to his HIV stories, which he gladly shared, I was not attuned to the new concerns that bothered him. I wanted to be of help to him, as he had begun to confide in me. However, I did not know how. I wondered if he saw me as a benefactor of sorts because I reimbursed him with $5 every time we met. While the genuineness of his need was beyond doubt, and in realizing that the cost of the lunch we had just eaten would have met his weekly grocery needs, I was deeply troubled. Mortified by his telling, I was unable to carry on with eating my lunch. I rested my spoon on the plate, wondering if he had any expectations of me regarding his financial situation. Why was he sharing them in the first place? I wondered about my moral and ethical obligations towards Luanda as a researcher. Was I still a researcher to him or a friend? Was it enough just to know that he lacked basic needs such as food? I had many questions.

As we cleared our plates, I realized how ill equipped I was to hear the social concerns that he presented to me. I did not imagine that participants' stories would challenge the researcher-participant relationship in the way they did. I really wanted to respond to Luanda, somehow. If I gave him money to sort out his financial situation beyond the $5 that I reimbursed him for "bus fare" to meet me for the research, how would that impact our relationship? If I remained ambivalent, how would our relationship move from that day on?

Another thing that bothered him on this occasion was the massive layoff of his colleagues at Utumishi. As a contractual employee, he too felt very vulnerable and uncertain regarding his job security. I sensed tension in him as he struggled to express this concern. Given that this had been his livelihood for the previous 3 years, and considering that he had used this job to secure bank credits, he was certain that a job loss would also mean defaulting on the loans he had. For once, he felt disconnected with the ASO, which in our earlier conversations was sentimentalized with glowing adjectives. At this juncture, he was no longer the enthusiastic Utumishi servant.

During the 30-minute lunch, I found Luanda to be direct in his telling about the issues that bothered him. His smiles were few and far between, and at some point I wondered if I was beginning to see the real Luanda. Was he wearing a façade all along with the sentimental stories of his relationship with Utumishi? Did his forthrightness have to do with spending more time together away from Utumishi that made him more candid about his life? As we parted ways, we agreed to meet for lunch one more time before I left for Canada in a week's time. I kept on pondering the issues that Luanda had raised in our lunch meeting. Being privy to his socioeconomic circumstances, I began to wonder if Luanda felt meaningfully engaged in HIV work. Was he drawn to this work for financial gain? I wondered if meaningful involvement in HIV work should translate to financial gain. Did he feel tokenized by the work he did?

Exactly one week later, I let Luanda decide a venue for our last lunch meeting together before I returned to Canada. Earlier in the day, he had told me that although he was on leave, he was planning to come to town to meet me and do other transactions. We agreed that we would meet at 1 pm. I proceeded to town as it was beginning to rain, to avoid the traffic congestion that a rain brings to Ukweli. Luanda was held up for 2 hours because of the rain and when it subsided, he quickly proceeded to town. He found me waiting at the agreed spot. I let him lead me to this latest "joint"[28] that he wanted us to venture into. I asked him to be mindful that a relatively quiet venue would be ideal for our conversation.

The restaurant he took me to was a newly renovated butchery that also served meat—roasted, boiled, and fried. The aroma of roasted meat saturated the air and we could see attendants in blood stained coats running back and forth to attend to the demands of clients. Customers shouted to attendants demanding answers about why their orders were delayed and others just made a nuisance of themselves. At this hour, at its peak, the eatery was chaotic, noisy, and packed to capacity. There were no empty spaces and a line of waiting clients extended several meters outside the door. Seeing that we struggled to find space, I suggested that we go to an alternative hotel. However, from the look on his face he seemed uninterested and instead was

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[28] A slang for a place to socialise.

determined to eat at this place. Finally, we found an empty spot at the corner of the room with only two chairs.

As we waited for the orders to be placed, he told me that he found it hard to stay at home when he was on leave, and often found himself at work, sometimes to connect with friends or to do some work that would keep him busy. This was not the first time that Luanda had told me how he disliked staying at home with his family whenever he was not at work. I wondered why he did not value spending time with his family. Was there tension that he was avoiding in the family? Luanda also told me that it had been a long time since he had eaten roasted meat. He felt honored that I asked him to choose a place to have his lunch. Coming to this butchery allowed him to inhabit a space where people with disposable income went to savor the finest roast beef in town. I wondered what made this place popular with men. Were the food prices cheap? Where were the women? Do they not eat roasted goat meat? I wondered if coming here reminded him of his life as a travel consultant, when he did not struggle to eat whatever he wished.

We rearranged the table and spread our bags onto the empty chair that had just been vacated so that no one would join us. Finally, our orders arrived. Luanda had ordered a ¼ kg of goat meat roast with ugali[29] and vegetables. His face beamed as the aroma of steaming meat spread around him. For the third time in this meeting, he mentioned how he had longed to eat goat meat, which he had not eaten for months. If Luanda had not eaten meat for this long, I imagined that his family too had not eaten meat in the recent past. I felt rather uncomfortable that I was providing Luanda with food that he could not provide for his family. Was it ethical that I was providing him with a "special delicacy," yet not extending the same to his family? Did I

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[29] Corn floor cake commonly eaten in Eastern and Southern African countries.

have any obligation to his family in that regard? I recalled that he had mentioned that his daughter had been nagging him to buy her meat during the last lunch we had together. Unable to meet the demand of a child was the worst assault to manhood that Luanda had expressed to me. I remembered the fawning face, full of guilt and shame because of this perceived deficiency. I was mindful that the stories of his socioeconomic struggles had overtaken HIV stories, taking preeminence in his tellings. I wondered what had caused this shift.

I struggled to attend to what Luanda was saying because of the noise that was coming from the restaurant. For the third time he raised his concern about his job security. He seemed paranoid regarding his fate as potentially the next person to lose his job. He thus lived in perpetual fear that a dismissal letter was inevitable. To cushion against the possible job termination, Luanda enrolled for a degree in counselling having successfully graduated with a higher national diploma a year previously. He told me that he could not afford the tuition of Kenyan Shillings 120,000 (CAD 1500) needed for the first year of the degree program. Embarking on a project, which he could not afford, heaped more frustration on him.

> How Luanda's story had evolved over the 3 months we have been meeting! From this last lunch, it became clear to me that his story about his passion working for Utumishi had evolved considerably. Not long ago, John referred him as an Utumishi's "servant." He also had told me his work is a calling. Now he sees himself as an insecure and insignificant employee uncertain about his future. Was it a reality check? What had he heard and seen? Was he putting a façade at the beginning of our conversation- to impress me on how passionate he was about Utumishi? I had no way of knowing (personal reflection).

> Today, I am in a mixed emotional place because when Luanda shared his financial and social problems with me, I did not know how to respond. Do I give him money? Am I allowed to empathize? Does he see me as someone with some privileges and access to money that I can

> help? And if so, how do I present myself in such a way that I do not become someone perceived as having money? How do I not respond when his needs are legitimate? What responsibility do I have towards my participant that allows me to decide what I can give to them? How do I maintain a meaningful engagement with him that is purely academic and not social? How do I hear his problems? (Field notes, 2013)

There were many moments of silence in this conversation between Luanda and me. I wondered about what to tell him when he bombarded me with his needs and anxieties. Was the silence an afforded opportunity for me to respond? I did not know what to do. Did the change of our meeting venue create a space for an opening of heart? Did he see me in a different light? After we cleared our plates, we washed our hands and headed out to create room for waiting customers. I was mindful that little Anabel had not eaten meat for long, according to Luanda's telling. Since I only had enough money to buy a ¼ kilo of meat, I handed the piece of meat to Luanda to take to his family.

Despite the noise emanating from the hotel, I was glad that we created a space where we engaged with issues close to Luanda's heart. I told Luanda on our way out that this was to be our last time together. I promised that I would keep in touch. Two days before I left for Canada, I called him to inquire what pseudonym I should use when I was writing about him. He chose the name Luanda, a legendary pre-colonial Luo leader renowned for his military exploits. In Dholuo dialect, Luanda means Rock, an attribute that befits his personality or so I thought.

Chapter 8: Exploring the Meaning of Living with HIV as a Chronic Illness in Kenya: A Narrative Inquiry

Abstract

Since the introduction of antiretroviral medications, HIV has been regarded a chronic illness. However, people living with HIV continue to experience social consequences of HIV infection such as stigma, discrimination, violence, and other human rights violations. In this paper, I focus on the experiences of Atoti, a person living with HIV in Kenya. I argue that HIV remains a biographically disruptive and exceptional illness that is complicated by its invisibility and unpredictable trajectory. From the participants' experiences, I argue that Bury's (1982) concept of biographical disruption often used to explain the social processes of a person suffering a chronic illness, does not fully capture the complexity of experiencing living with HIV. Focusing on life as a whole, rather than on the disease response and process as a biographical disruption, allows for a deeper appreciation of HIV's complexity as a medical illness with major social ramifications.

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Introduction

> *My name is Atoti and I have been living with HIV since 2002, when I was diagnosed in an antenatal clinic. At the time, my husband was HIV negative but seroconverted 5 years later. My family and friends stigmatized and abandoned me when they learned of my HIV status. Subsequently, I suffered loneliness, persecution, rejection, shame, and poverty. I joined an HIV support group at a time when my self-esteem was eroded and I lacked motivation to live. This organization has helped me to accept myself, overcome stigma, and develop a network of friends and I now live positively with HIV infection. This organization is for clients like you and me. I plead that whatever we will share here, remains here. You can greet me if we meet outside there, but never raise HIV issues with me there* (a direct quote).

My first research encounter with Atoti came as an observer of an HIV education presentation that she gave to people living with HIV and AIDS (PHAs) in an AIDS Service Organization (ASO) where she worked as an HIV lay worker. In this presentation she covered topics such as adherence to antiretroviral (ARV) treatment, good nutrition, and HIV disclosure. By using her own experiences, Atoti made the presentation relevant to her audience and as an observer, I was awed by her composure and confidence as she shared sensitive and intimate personal details of her life. However, I did not know what to make of Atoti's warning to her audience not to acknowledge her HIV status outside of the ASO's building. I wondered: Were there places or situations when Atoti was uncomfortable to be known as a PHA?

During her five minute presentation, Atoti covered her own experiences of living with HIV from the time she was diagnosed with HIV, the social consequences of other people knowing her HIV status, her diverse turning points, and how she lived positively with HIV infection. In the presentation, Atoti shared that when she was 6 months pregnant she was offered an HIV test as part of a routine antenatal visit. Although she accepted the test, she was not prepared for the results. Following the positive HIV diagnosis, she was subjected to gender-based violence, stigma, discrimination, abandonment, and isolation from family and friends. In referring to herself as “I am a person living with HIV,” Atoti embodied an expression of her realities, identities, hopes, and aspirations. How she managed to accept her HIV status and began living positively with HIV was of great interest to her audience who deemed her a hero who had succeeded in “slaying the HIV monster” to live a positive HIV story.

In this paper, I highlight some of the findings from a larger research study to explore the experiences of people living with HIV in Kenya of which Atoti was one of the four participants. I explore how Atoti constructed her experiences living with HIV and analyse these experiences using Bury’s (1982) framework of biographical disruption to identify diverse events and critical moments that shaped her HIV identity. Utilizing Bury’s (1982) concept of illness as biographical disruption, I highlight HIV as a unique chronic illness due to its biomedical and social impacts and peculiarities.

Literature review

Bury (1991) defines chronic illness as a long term and perhaps permanent event in a person’s life, characterized by dependency and regression that disrupts the structures of everyday life and forms of knowledge that sustain an identity (Bury, 1982). As a biographical disruption, a chronic illness undermines the self, erodes a sense of identity (Charmaz, 1983), causes a loss of confidence in the body and diminishes personal and social interactions (Bury, 1991). Subsequently, a person lacks will and ability to assert meaning and purpose, becoming dependent on external agencies to support a recovery or to maintain the continuity of daily life (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010). Giving meaning and voice to the illness experiences supports one’s acceptance of the illness and access to resources to maintain a sense of continuity of life. Biographical reinforcement, reconstruction or reformulation of an identity become avenues through which a person with a chronic illness makes sense of a situation (Bury, 1991; Carricaburu & Pierret, 1995; Williams, 1984; Wilson, 2007). As a social process that seeks to explain an illness, biographical disruption is based on the assumptions that: a) an illness disrupts the taken for granted assumptions and behaviors that breach common sense boundaries through bodily changes that, though insidious, make one aware of the illness; b) an illness causes a rethinking of a person's biography and self-concept, calling for an appraisal of the impact of the illness on self, body, living, and relationships and; c) a person with a chronic illness mobilizes resources in response to the disease process (Bury, 1982).

HIV Diagnosis

> *I am sure I was HIV negative at the time I got married to him. Before I got diagnosed with HIV, I was just a house wife that depended on my husband to provide. My husband used to be unfaithful to me. He loved pleasure and women.*

Before her diagnosis with HIV, Atoti composed her identity in relation to the taken for granted identities of being a mother, spouse, and a member of her community. She lived according to the culturally prescribed gender expectations, storying herself as an innocent, helpless person, victimized by HIV viciousness that disrupted her social fabric and challenged her sense of identity. Being diagnosed with HIV significantly transformed Atoti's identity with cascading dire social consequences. HIV became a reference point through which her other subsequent experiences were lived and told. Medically speaking, while a positive HIV antibody test confronted Atoti with the "possibility of an altered body, self, and breach of every day realities" (Tewksbury, & McGaughey, 1998, p. 217), it was the disruption of her being, her position in the family and society that had the biggest impact in Atoti's life. The HIV diagnosis limited her socioeconomic realities and opportunities for socialization. In addition, it posed a potential loss of health, a premature disability or mortality, and a loss of identity (Ciambrone, 2001).

Despite the advanced HIV care that has transformed HIV into a chronic illness, Atoti's HIV diagnosis was a life defining moment for her, causing mental and psychological trauma, shock and depression. This experience is consistent with findings that HIV stigma and discrimination damages PHA's self-esteem, self-image, and self-concept and hinders their ability to ascribe meaning to their lives (Leserman, 2008; Mill et al., 2009; Plattner & Meiring, 2006; Whetten, Reif, Whetten, & Murphy-McMillan, 2008). In addition, HIV disrupted Atoti's social organization, forcing her to contend with social structures in order to embrace an HIV identity and maintain a sense of wellbeing.

Methodology

I utilized narrative inquiry to inquire into Atoti's experiences of living with HIV. Narrative inquiry is a way to understand and inquire into the experiences of people through the stories they live and tell (Clandinin & Connelly, 2000; Clandinin & Huber, 2002). Philosophically, narrative inquiry draws on Dewey's theory of experience (1938) which posits that every experience is constituted by interaction between subjects and objects and between self and the world. Narrative inquiry is based on the assumption that human beings live and tell their stories as a way to interpret their world (Connelly & Clandinin, 2006), opening up possibilities for meaning making and new identity formation (Bruner, 2002). Further, stories are ways through which experiences are organized to reconstruct reality with the available cultural and linguistic frames of reference (Bruner, 1991; Crites, 1971). Through narratives, an illness is given voice by depicting its role in shaping personal conduct, response, and adaptation to pain (Frank, 1995; Hydén, 1997). Hydén (1997) further asserts that by living and telling illness narratives, the transformation of an illness to a collective phenomenon is made possible.

Narrative coherence is a vital component in making meaning of a life disrupted by an event such as an illness, allowing the teller to connect past, present, and future, and giving unity and purpose to the teller (McAdams, 1988). Coherence is attained by arranging fragments and episodes of life into stories and by connecting the internal, cognitive, and affective condition of the teller (Klein & Boals, 2010). To live a narratively coherent life, one must recognize the transcendent nature of story in which "human beings have and continue to draw on stories as a way to share and understand who *they* are, who *they* have been, and who *they* are becoming" (Huber, Caine, Huber, & Steeves, 2013, pp. 213–214). Autobiographical narratives convey stories to live by, a narrative reference to identity which is "composed in storied form and shaped and lived in places, in actions, in relationships with others, in language, including silences, in gaps and vacancies, in continuities and discontinuities" (Clandinin & Huber, 2002, pp. 161–162). By giving credence to the importance of autobiographical narratives in identity construction, Fivush and Buckmer (2003) observe: "we each author our own lived story. In constructing and recounting our past, we are simultaneously constructing and reconstructing ourselves. Who we are is very much created through autobiographical narratives" (p. 149).

Life history research therefore acknowledges the interactive relationships between individual life's perceptions and experiences and shows how individuals negotiate identity and make sense of their lives and their roles in their social worlds (Goodson & Sikes, 2001). It also links together events, experiences, and perceptions and becomes a basis through which identities are formed (Goodson & Sikes, 2001). In utilizing life history research, a participant is able to confront a preconceived and predetermined subjective perception, revealing the details of life, experiences, and perspectives that otherwise are inaccessible (Goodson & Sikes, 2001). In looking at Atoti's life as an autobiographical composition, I rendered voice to her experiences, enabling her to celebrate the important aspects of her individual existence (Smith, 1998).

A narrative conceptualization of experience incorporating the three dimensional inquiry space of time, place, and context (Clandinin & Connelly, 2000) informed my understanding of how Atoti's experiences with HIV unfolded. In particular, I paid attention to how HIV was transformed over time; HIV became a metaphorical marker that signalled critical moments in Atoti's life. The sociocultural context and her relationships with significant others informed the way her experiences of living with HIV were shaped and expressed. Utumishi[30], an AIDS Service Organization where she was a client and an employee, was a place that was laden with symbolism and meaning. Atoti storied the AIDS Service Organization as a source of her redemption and a second home where her HIV issues were addressed.

In the 3 months I engaged with Atoti, I wrote extensive field notes, held formal conversations, and visited social places alongside her. In so doing, I tried to comprehend the explicit and nuanced aspects of her life through verbal and nonverbal expressions that resonated with her HIV experiences. I wrote narrative accounts emanating from the field texts, juxtaposing personal reflections and experiences beside the accounts. In upholding and pursuing relational

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[30] The name Utumishi is a pseudonym for the AIDS Service Organization where Atoti worked and is a Kiswahili word for 'service'.

ethics, I negotiated the interim texts with Atoti and refined the accounts based on the feedback she gave. This negotiation occurred during a subsequent 2 month visit to Kenya.

Living and Telling Life Stories

At the beginning of our conversations, Atoti was self-assured, composed, and collected but displayed a guarded disposition. However, with time, this predisposition dissipated, especially when she told sensitive stories about her life with HIV. As the details of her stories changed, so did her comfort to exhibit emotions that corresponded with the stories she told. Although Atoti's stories were not told in any particular order of significance, the changes in the intonation and the intensity of mood as she lived and shared them conveyed the weightiness of particular stories. In this paper, I have presented her experiences in a temporal way, from her pre-HIV narratives to her narratives as she embraced an HIV identity. This allowed me to give her narratives a sense of coherence.

The pre-HIV narratives were given particular pre-eminence as she told them and they revolved around her youth and early days of marriage, setting the stage for the unfolding of a life with HIV. At first, as she shared her earliest recollection of significant events and moments in her life, I did not know how to make sense of them and even wondered how they fit in the overall picture of her HIV identity. However, by retelling her experiences, she revised her biography, and the previous mundane stories of growing up and teenage motherhood became events when her personal vulnerabilities to HIV were awoken, revisited, and relived. Stories of her youth and her marriage comprised the pre-HIV narratives that she told.

As a teenager, Atoti described herself as a naïve, innocent, and vulnerable victim of gender-based power imbalances. She developed a sexual relationship with her high school teacher; an encounter she later believed was an example of being taken advantage of by someone in a position of trust and power:

> *I was 16 years and I had joined Form One [Grade 9] and I was sexually active with a boyfriend. I began to date the teacher because he had the money to meet my needs. I became pregnant by him twice, and thereafter, he left the school he was teaching to pursue further studies. Out of frustration, I decided to come to town to look for something to do.*

At the time, Atoti felt privileged to have a teacher for a boyfriend who doted on her with numerous financial and sexual favours. However, the passage of time allowed her to reflect on the meaning of this experience. Blaming these teenage experiences for many missed opportunities, she came to regard them as focal points through which she could explore the idea of vulnerability to HIV infection. In looking back, Atoti realized the extent to which her teenage pregnancies had impacted her life, including the choices and opportunities that became available to her. Hence, her teenage years were recognized as a critical time when her life trajectory was altered, awakening her to heightened vulnerabilities.

> *I do regret (dropping out of school) because I never finished high school, yet my parents were able to take me to school. Now I am paying for my lack of schooling, by attending adult literacy classes. Studying is hard at my age because of competing domestic chores, interests and other financial obligations.*

Atoti's lack of formal education was a barrier to many academic and employment opportunities. As a teenage mother, Atoti matured faster than her biological age in order to assume parental responsibly for her children. Becoming a lowly paid domestic worker, earning CAD $7 a month, was her only way to earn a living. In the course of her work, she met and married Martin. Through marriage, she hoped to redeem her personal image, acquire a new identity, and develop a sense of belonging. Before getting married, Atoti insisted that Martin meet all cultural obligations required of marriage in order to feel secure and assured of her position as a legally married woman.

> *Martin was living in the same rental houses as my sister whom I visited frequently during my time off from the work I did as a nanny. The more I visited, the more we became acquainted to each other. Later he told me that he wanted to marry me. I told him about the children I had and my past. I insisted that we visit my parents before getting married, as I wanted to be sure that we were doing it properly. He was compliant to my request and even paid dowry.*

Even though Atoti looked forward to getting married, she was aware of the importance of a premarital HIV test. However, she was unable to ask Martin to take an HIV test because she did not want to appear untrusting of Martin's integrity. After all, Martin's healthy physical appearance gave her some assurance that he was HIV negative. Atoti now bitterly regrets her sense of helplessness and lack of courage to ask Martin for an HIV test as a precondition to marriage.

> *I did not ask for an HIV test because he looked strong and was not sickly. . . . I regret that we never tested for HIV before we began staying together. I do regret sometimes because living with HIV requires [a] lifelong commitment to taking medications.*

Atoti was confident in her own HIV status before marriage, and of her marital fidelity to her husband. Nevertheless, the threat of HIV infection was always before her, and there were personal, cultural, and gender barriers that limited her ability to protect herself from HIV within marriage. This fear was confirmed at an antenatal clinic when she was 6 months pregnant. When she was offered a routine HIV test, it turned out to be positive for HIV antibodies. At the time, she doubted the results, dismissing it as a false positive result, and continued with her usual life. Four years later she was tested for HIV in a similar circumstance; with similar results, she decided to inform her partner:

> *In 2000, I went to the antenatal clinic for follow-up, and I was tested for HIV as part of antenatal care. I took it as a false positive and as such, I did not disclose to anyone. In 2004, I became expectant again and went to the antenatal clinic. I retested and was found to be HIV positive. It was then that I decided to tell my husband whose test came back negative. I was shocked that I was HIV positive and my husband was not, and felt as though my world was crushing beneath my feet.*

Atoti believed that Martin was HIV positive at the time of marriage, although she was unable to explain why his HIV test was negative. Nevertheless, her two HIV positive results in a span of 4 years were sufficient proof of her HIV status. She hoped that Martin would support her at her most vulnerable moment; pregnant and now living with HIV. Martin reacted violently to her HIV positive diagnosis and eventually deserted her, leaving her to face tremendous HIV stigma and discrimination alone. Rejection from her family and the community that followed her HIV diagnosis disrupted Atoti's identities as a mother, a spouse, and a member of the community. The HIV diagnosis became Atoti's major turning point that drastically shaped her identity including her personal, social, and communal relations.

> *At night, my husband became physically and emotionally violent, accusing me of unfaithfulness; as I was HIV positive yet he was not. My neighbors heard all the commotions as our houses were crammed together. Three days later, my husband left me with my children, to our upcountry home, telling family and relatives that I was infected with HIV. As a housewife with no income, fending for my family while pregnant became a nightmare. Unable to raise the house rent, I decided to follow my husband and while there, I learned how he had damaged my name and reputation by disclosing my HIV status. My mother-in-law segregated me from my children; making sure I ate in seclusion and no one shared my utensils. Soon, my husband married another woman. Desperate, I returned home to find that neighbors had learned of my HIV status. They taunted me with songs and refused to share toilet facilities with me, alleging that I would infect them with HIV.*

Atoti's HIV diagnosis challenged her assumptions about her social standing in her family and in the community. Soon after her HIV diagnosis, she was unable to prevent familial disintegration or to plead her innocence. The desertion by family and friends led to a rapid erosion of her identity which brought more trauma than the HIV infection itself.

Rethinking Atoti's Biography and Self-concept

> *Life with no source of income was getting harder by the day. Poverty drove me to prostitution and drinking illicit brews. I withdrew my first born son from school to take care of my other children so that I can concentrate on my brewing business. When not selling the brew, I would go to town for sex work.*

The social exclusion by family and friends left Atoti fighting for her survival and that of her children. Despite personal and cultural taboos, and painful as it was, Atoti engaged in sex work and peddling of cheap alcohol brew in order to survive. Although she was fully aware of the damage to her identity that engaging in sex work would cause, Atoti had no other viable alternative to pursue. By overcoming her personal and cultural reservations about becoming a commercial sex worker, Atoti learnt independence, endurance, and determination in the process.

Reliving and retelling her experiences as a commercial sex worker was one of Atoti's most devastating experiences after her HIV diagnosis. She regarded this as the darkest moment of her life; a time when she felt her life had lost meaning. Atoti was also distraught when she recalled sacrificing the future of her children by withdrawing them from school, partly due to a lack of school fees and partly to enable them to be involved in her brewing business. Who she became as a PHA was informed by the social, economic, and cultural resources she was able to access. In reliving this story, the complexity of the relationship between HIV, gender, poverty, and stigma and how they shaped Atoti's personal response to HIV was exposed.

Mobilisation of Resources and Rebuilding of a Life

HIV infection eroded Atoti’s will, energy, knowhow, and ability to reach out for help in order to live positively as a PHA. By chance, she met a nurse who visited a hospital where her son was admitted with a chest infection. The nurse informed her of services available for PHAs at a local AIDS Service Organization. Atoti also shared her story with the nurse, and after discharge the nurse gave her some money to start a small business. Afterwards, the nurse enrolled Atoti in an HIV support group where PHAs met on a weekly basis to share their experiences and to encourage and support one another:

> *In the support group meetings, I was amazed at the ease in which people living with HIV gladly shared their lived experiences. It was there I learned that [the] majority of them were having grave challenges such as loss of their loved ones, single motherhood with many dependents, abandonment, [and] discordance among others. I also learned how they lived positively with HIV and how they sustained themselves. I was transformed by these meetings [so] that I felt empowered to seek informal employment to support my family. I reenrolled my children to school, regained lost weight and my CD 4 count went up.*

The support group meetings became a platform through which Atoti rebuilt her life and where personal validation of her own experiences occurred. No longer ashamed of the life she had lived, Atoti found a place, space, and courage to share and relive her experiences. Over time, her confidence grew and her self-esteem was restored. Through the support group meetings, much of the social harm that had resulted from her HIV diagnosis seemed to be alleviated. By attending to the experiences of other members of the group, she felt supported and began to embrace her own HIV status and began living positively with HIV. Three years after joining the support group, Atoti was hired as an HIV lay worker at the AIDS Service Organization having demonstrated a capacity to be an HIV educator, leader, counsellor, and a peer navigator. In her post HIV diagnosis identity, HIV had been metaphorically transformed from a veracious agent that brought misery and hurt, to a positive agent that created opportunities for financial, social, and personal emancipation. Atoti cherished the opportunity to relive the journey of accepting her HIV status.

> *When I joined the support group, I learned among other things, the art of disclosing my HIV status to other people and sharing my experiences. With time, I became comfortable disclosing my HIV status. Now each morning, working at the ASO as an HIV lay worker, we give health education to our clients who comprise pregnant mothers, singles, men and women of all ages. We begin by relating our experiences to them, then we share structured messages to clients such as adherence to HIV treatment and how to disclose HIV status to others.*

By accepting her HIV status and living positively with HIV, Atoti attained clarity in identifying strategies to rebuild her life that had been impacted by her HIV infection. Atoti's family, an important part of who she was, had been adversely affected by her HIV diagnosis; this had serious social consequences. Five years after Martin deserted her, he came back to the matrimonial home, having seroconverted to being HIV positive. Having accepted his HIV status meant that Atoti had developed the capacity not only to forgive, but also to support her partner who returned to her gravely ill. The cost of restoring her family to what it once was immaterial, compared to the joy that the reunion brought. By her own confession, the post-HIV marriage dynamics were radically different from the pre-HIV marital climate. By giving their marriage a second chance, both Atoti and Martin experienced the happiness, trust, companionship, and respect that had been absent before. HIV, now a common denominator in the marriage, became a provider of opportunities and a source of social support:

> *Before I got diagnosed with HIV, my husband used to be unfaithful to me. He loved pleasure and women. Since he got to know his HIV status, we have fallen in love again, trusted one another and I can see there are lots of changes in our marriage after we got*

> *back together as PHAs. So our status has made us love one another. My husband clearly loves me more than before and he is also faithful to me.*

In addition to having her marriage restored, Atoti and Martin have since had four more children, all of whom are HIV negative. Atoti had also reenrolled in school to complete her high school diploma that she had abandoned 20 years previously. She hoped to become a counsellor and to take advantage of the numerous opportunities that HIV has presented to her. Furthermore, unlike her pre HIV state, Atoti was now economically productive, independent, and the main provider for her family:

> *Before knowing my HIV status, I was just a house wife that depended on my husband to provide. . . . So to me, being infected with HIV has opened many doors. I have bought land where my home is and even looks after nine children, six of whom are HIV orphans. Although the houses are semi-permanent, and my husband is jobless, I am able to meet our daily needs through the job that I do*

At the time of our conversations Atoti had not experienced any severe physical consequences related to her HIV infection since she was diagnosed with HIV. She was diagnosed with HIV and started on antiretroviral medications before developing any physical signs and symptoms of AIDS. Her only reminder of her HIV infection was her daily ARV medications.

Discussion

Atoti lived with HIV as a chronic illness due to the availability of antiretroviral medications that she dutifully took. In my endeavour to understand how she experienced her HIV infection, I recognized that many of her experiences resonated with Bury's (1982) concept of biographical disruption. Bury drew from the experiences of patients suffering from rheumatoid arthritis, also a chronic illness, to inform the concept of biographical disruption. In this concept, Bury identified three fundamental elements that a person experiencing a chronic illness may encounter. These elements include: an illness disrupting the taken for granted assumptions that challenges the common sense boundaries; an illness causing a rethinking of a person's biography and self-concept; and an illness resulting in the mobilization of resources in response to the chronic disease.

Based on my interactions with Atoti, I recognized that although HIV was a biologically disruptive illness, her experiences could not be fully explained by the concept of biographical disruption. This is because of HIV's unique medical and social characteristics. To begin with, HIV challenges the dichotomy of the disease classification of infectious (acute) versus chronic illnesses because it possesses these two characteristics (Nigatu, 2013). Further, the chronicity of HIV is contingent on an individual's adherence to antiretroviral treatment modalities, without which HIV remains a fatal disease. Unlike other chronic illnesses, HIV infection has a long lasting socio-economic and political impact (Smith & Whiteside, 2010) that goes beyond the individual to affect societal and cultural dynamics. In addition, while the impact of an HIV diagnosis is somewhat predictable, the trajectory of the development of AIDS is unpredictable. There may be a long latency period from the time of HIV infection to the appearance of symptoms, and the development of AIDS (du Plessis & Bezuidenhout, 2009).

In addition, antiretroviral medications have made HIV invisible. Therefore, fewer people develop symptoms of AIDS. The lifelong dependency on ARVs that halt the disease's natural progression inevitably makes HIV a manageable and chronic illness, yet it too remains an unstable illness. Moreover, the "conventional understanding of a *chronic* disease as a condition that is stable, manageable and lifelong, without acute signs does not adequately address or capture life with HIV for most people" (Covin, 2011, p. 4, italic added). While the first concept of biographical disruption is based on a particular symptomatic manifestation of a disease as an indicator of the presence of an illness, the invisibility of HIV due to its unpredictable latency means that PHAs do not always present with symptoms that identify them as such. In Atoti's case for instance, a routine antenatal clinical appointment became the avenue through which her HIV diagnosis was made at a time when she was asymptomatic.

The second aspect of biographical disruption that is relevant to Atoti's experience relates to a fundamental rethinking of a person's biography and self-concept following the onset of an illness. According to Bury's concept of biographical disruption, this process begins with a confirmatory medical diagnosis which objectifies an illness as "separate from the individual self" (Bury, 1982, p. 172). Following a diagnosis, an individual is thus confronted with pathological and social demands of the illness. In Atoti's case, while two HIV tests confirmed her HIV positive status, the social consequences of the HIV diagnosis and not the medical uncertainty, caused her to rethink her biography and self-concept. This rethinking was spurred by the complex social and cultural connections surrounding HIV infection (Lekas, Siegel, & Schrimshaw, 2006; Parker, & Aggleton, 2003). In Atoti's situation, stigma in particular created a power imbalance that provided a platform for blame, segregation, labelling, and stereotyping (Alonzo & Reynolds, 1995; Link & Phelan, 2001).

Depression and hopelessness that are often associated with HIV stigma erodes self-esteem and self-worth. This is compounded by a lack of social support and significantly shapes the quality of life for persons living with HIV (Holzemer et al., 2009). In particular, a woman living with HIV is likely to experience human rights violations such as domestic violence as part of her HIV diagnosis (WHO/UNAIDS, n.d), particularly in sub-Saharan Africa. To Atoti, rethinking her personal biography was a response to the social impact of HIV infection that led her to poverty, homelessness, destitution, and social isolation. This is congruent with Mill and Anarfi's (2002) findings that Ghanaian women's vulnerability to and experiences of living with HIV were aggravated by unequal power relations and poverty. The erosion of a personal identity led Atoti to engage in transactional sex as a commercial sex worker in order to survive.

Resources are vital to maintain continuity of life and an overall sense of wellbeing with a chronic illness. Mobilization of resources to normalize the disruption caused by an illness, a third aspect of biographical disruption, is often dependent on individual agency, socioeconomic status of the person, and the flexibilities in formal and informal relations (Bury, 1982). A chronically ill person can maintain continuity of life without seeking external help, a process Reeve and colleagues (2010) refer to as biographical flow. On the other hand, biographical fracture occurs when an illness causes a loss of continuity in maintaining wellbeing, requiring support of others to do the same (Reeve et.al, 2010). In Atoti's situation, HIV had a devastating, yet invisible impact that destroyed her self-concept, esteem, and social network. Her illness eroded her will to live and the individual agency required to not only ascribe meaning to life, but also to make connections to enable her to access necessary resources. Therefore, she needed an external support system to guide her to a path of personal emancipation. The resources Atoti eventually mobilized also enabled her to rebuild her life and to attain personal, social, and economic transformation.

Although the concept of biographical disruption provided a basis to consider the social and adaptive processes of living with a chronic illness (Bury, 1982; Reeve et al., 2010), focusing only on the disease process does not do justice to both the internal and external processes that were at play for Atoti. Attending to life through the experiences Atoti lived and told brought out the visible and invisible, the medical and social, and the pre- and post-disease narratives that informed her identity. In organizing life in a temporal manner, critical moments that defined Atoti's life and reassigned meaning to her experiences, were identified. Further, a deeper appreciation of how diverse segments of her life came together and the emergence of her HIV identity became apparent. Atoti was therefore able to map events in her life that brought to light diverse vulnerabilities that shaped her experiences. For instance, by retelling her teenage pregnancy experiences, gender based power imbalances became explicit and the link between dropping out of school, early marriage, and her inability to negotiate HIV testing for her husband was made. By organizing the events that happened before and after her HIV diagnosis in a temporal way, it became apparent that these events were significant in formulating an HIV identity, giving coherence to her experiences. For instance, pre-HIV narratives became the basis through which HIV disruption was initially appraised and were a reference point through which her post-HIV aspirations were measured. Retrospective illumination (Ruddick, 2005) of her past experiences through reliving and retelling her pre-HIV narratives allowed her to revise her biography, by assigning new meaning to her experiences of teenage pregnancy, working as a nanny, and her early marriage.

A focus solely on the disease process, as is the case with Bury's (1982) concept of biographical disruption, therefore, overlooks events that precede a critical event and the personal transformation that may follow a critical event. By attending to the totality of Atoti's life, how she organized her telling, what stories she chose to tell, the meaning attached to each of the stories she lived and told, and who she became by living these narratives, was made explicit. In supporting the construction and sustainability of an HIV identity, a person living with HIV is able to imagine the genesis of their HIV illness and the factors that shaped the development of an HIV identity alongside other identities (Rost, 2005).

Atoti experienced personal transformation through the experiences of living with HIV. These transformations are also marked as “moments of growth” or critical moments that changed the way she perceived her HIV infection. As she lived and told her HIV stories, I imagined how HIV had *metamorphosed* in her life from before an HIV diagnosis to embracing an HIV identity. For instance, before she was diagnosed with HIV, she regarded HIV as a *dreaded one*, depicted by her fear of HIV infection and acknowledging her inability to protect herself from it. HIV became the *destroying one*, after her HIV diagnosis, which led to devastating social consequences destroying her being, way of life, and social relations. Finally, HIV became the *rewarding one*, signaling an acceptance of her HIV status and the opportunities it provided, allowing her to be economically productive, to rebuild her family and career, and look forward to a fulfilling future with HIV.

In representing her HIV experiences narratively, Atoti brought out the reality of her life with HIV in a way that was understandable. Bruner (1991) asserts that in utilizing narratives to attend to life experiences, participants can be understood as actors in a particular setting; reliving their experiences in relation to their beliefs, values, and desires. Further, Dewey’s (1938) asserts that human beings learn from experience and that with time, they accumulate experiences which influence future experiences. In Atoti’s case, the accumulated experiences of living with HIV became a repertoire from which she drew knowledge to educate and support HIV clients. In sharing her experiences, Atoti’s HIV stories acquired meaning and structure, forming a basis on which other stories were lived and told. By using locally available and relevant metaphors and language to describe the events in her life, Atoti's experiences were consistent with Bruner's (1991) assertions that narratives are not just a form of representation, but help to constitute reality.

Therefore, in attending to the whole life of a person, one is able to explore personal and social processes that are key in understanding a particular experience. Furthermore, narratives allow one to understand how a person living with HIV negotiates contextual and relational imperatives to fashion and embrace an HIV identity. In this paper, I reinforce the idea that HIV infection, though a biomedical disorder, has major social ramifications and that the contemporary trend to define HIV as a chronic illness addresses only part of its complexity. While antiretroviral medications and 'do it yourself' HIV home test kits (FDA, 2015) have succeeded in normalizing HIV infection, they only reinforce the notion that HIV is largely a medical problem, best addressed with biomedical solutions. However, despite the medical advances in HIV care, the social aspects of HIV remain. If HIV medical gains are to be sustained, and an improvement in the quality of life for PHAs achieved, social investments and supports for people living with HIV need to be reprioritized. The experiences of Atoti helped me to understand HIV as an invisible disease with a chronic status that is fluid and unstable. The medicalization of HIV, hinging on the idea of chronicity, obscures the social processes and implications that are called forth by HIV. In regarding HIV as a biographical disruption, attending to the totality of life is key.

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Chapter 9: Involvement of People Living with HIV in a Kenyan AIDS Service Organization

Abstract

Since the first HIV case was reported in 1981, people living with HIV and AIDS (PHAs) have sought active involvement in HIV work under the auspices of the principles of greater involvement of people living with HIV and AIDS (GIPA). In Kenya, people living with HIV are involved in HIV work through HIV non-governmental organizations and AIDS Service Organizations, of which a majority are donor funded. Utumishi, a donor funded organization in western Kenya provides care to PHAs and also employs them to provide support, education, and care to its clients. In this narrative inquiry, I inquired into the experiences of four PHAs employed at Utumishi through living alongside them, visiting them in social places, and listening to their stories. Working with the three-dimensional narrative inquiry space of time, place, and social context, as well as incorporating Lindemann-Nelson's (1995) concept of found and chosen community, I inquired into the opportunities and challenges that PHAs faced in the implementation of GIPA in a local AIDS Service Organization in Kenya.

Key words: HIV; AIDS; Greater involvement of people living with HIV; GIPA; HIV lay workers; narrative inquiry, Kenya

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Introduction

Kenya's first person living with Human Immunodeficiency Virus (HIV) was identified in 1984, and for a time HIV infection was considered a foreign disease affecting specific groups of people including commercial sex workers, truck drivers, and youth (AVERT, 2014; National STIs Control Program [NASCOP], 2012). Due to this perception, the Kenyan government delayed its response to the HIV epidemic which allowed the epidemic to grow unmitigated, reaching a prevalence rate of 10.9% in 1996, the highest rate of the epidemic (AVERT, 2014). In 1999, the Kenyan government declared HIV a national disaster (Kawewa, n.d). Since the epidemic began, about 1.5 million people have died from HIV-related illnesses in Kenya (NASCOP, 2012).

Many governmental and non-governmental organizations (NGOs) were formed in response to the HIV pandemic. The National AIDS Control Council (NACC), a state corporation, was established in response to provide a "policy and strategic framework for mobilizing and coordinating resources for the prevention of HIV transmission and provision of care to infected and affected people in Kenya" (NACC, 2010, p2). The NACC and the Global Fund Country Coordination Mechanism are two prominent organizations that have utilized the expertise and experiences of people living with HIV (PHAs) to formulate policies and inform programming (NACC & NASCOP, 2012). Local HIV NGOs provide support and visibility to PHAs to engage in activities that reflect the Greater Involvement of People living with HIV and AIDS (GIPA) principles. The National Empowerment Network of People Living with HIV in Kenya (NEPHAK) brings together PHAs to enhance their knowledge and skills through advocacy, networking, alliance building, and sub-granting (NEPHAK, 2013). Subsequently, it has become a conduit through which PHAs have been involved in HIV work regionally, nationally, and internationally.

In the current study, my research puzzle focused on the experiences of PHAs involved in HIV care work. In particular, I was interested in the opportunities and challenges related to implementing the GIPA principles in an AIDS Service Organization (ASO). While attending to participants' experiences of living with HIV, visiting with them in social places, observing them at work, and listening to their stories, I began to wonder if and how they fulfilled the GIPA principles within their work.

Background to GIPA

GIPA has guided PHAs' involvement in HIV work since the principles were formulated in 1983 (Lune, 2007). These principles, outlining the rights of PHAs, were originally known as the Denver Declaration. This declaration, dubbed the origin of AIDS activism, mobilized the HIV community to advocate for PHAs' inclusion in HIV activities and for the allocation of resources towards HIV research, care, and prevention (Ontario AIDS Network, 2011; Wright, 2013). The Denver Declaration condemned the marking of PHAs as 'victims', 'patients', or 'socially dead' and coined the term People living with HIV and AIDS (PHAs) to replace these stigmatizing labels (Lune, 2007). The Denver declaration brought visibility to the plight of the PHAs and became the basis through which PHAs' involvement in HIV work was founded.

The AIDS Paris Declaration (1994), building upon the Denver Declaration, emphasized the need to fully incorporate GIPA in HIV work and advocated for the development of a conducive political, social, and legal environment at all levels of society to support GIPA activities (UNAIDS, 1999). In the 1994 AIDS conference, a commitment was made by 42 countries to make HIV a priority and to act with compassion for, and in solidarity with, PHAs and those at risk for HIV infection (UNAIDS, 1994, 1999). The signatories to this declaration also committed themselves to granting PHAs equal rights and protection to reduce stigma and discrimination, and to involving PHAs as partners (UNAIDS, 2007). The Meaningful Involvement of People Living with HIV and AIDS (MIPA) was popularized at the 1994 Paris Declaration based on a concern that PHAs were at times only engaged as "tokens" by organizations to fulfil GIPA requirements. To realize MIPA, PHAs were to be engaged in "meaningful ways where they have a real voice in decision making, in leadership and anywhere their expertise and experiences of living with HIV are both sought and valued" (Ontario AIDS Network, 2011, p. 13). In 2001, the Paris Declaration was ratified by the United Nations General Assembly as part of the Declaration of Commitment to HIV (United Nations, 2001). In 2006, the United Nations High level meeting on HIV/AIDS reaffirmed support for the GIPA principles (UNAIDS, 2007). The GIPA principles have become a tool through which PHAs endeavour to achieve "the right for self-determination and participation in decision-making that affects their lives" (UNAIDS, 2007, p. 1). A focus on the experiences of living with HIV is the guiding philosophy for GIPA involvement, which can inform HIV policy development, programs, and interventions (Jürgens, 2008; UNAIDS, 2007).

Although PHAs are central to the implementation of the GIPA principles, they are also burdened with the medical and social effects of HIV. People living with HIV, a disease that is now considered a chronic illness, are expected to adhere to certain 'normals' in health seeking behavior and sexual practices in order to minimize HIV transmission. In PHAs' endeavor to incorporate HIV into their identity making, PHAs must contend with a myriad of challenges, which also hinder self-management of HIV. These include social responsibilities, socioeconomic status, as well as social support (Sastre, Sheehan, & Gonzalez, 2015).

PHAs' involvement in GIPA activities across Africa is diverse. In Malawi, as expert patients, PHAs have been trained to provide care to other PHAs in the HIV clinic (Tenthani et al., 2012). In a project undertaken by Tenthani and colleagues (2012), PHAs provide basic nursing tasks, administer antiretroviral medications and provide counselling and support as a way to fill the human resource gap due to staff shortage in HIV care. In Uganda, PHAs have been involved in community mobilisation to access HIV care (Mburu, Iorpenda, & Muwanga, 2012). Through the provision of HIV literacy programs and referral to care, uptake of HIV services and a reduction in vertical transmission of HIV has been realised in Uganda (Mburu, Iorpenda, & Muwanga, 2012). In South Africa, PHAs' work as GIPA field workers has added credibility and value to the HIV programs and created a supportive environment for other PHAs to speak about their HIV status (UNAIDS, 2002). As expert patients, PHAs are able to provide compassionate care to fellow PHAs and relieve overburdened health care providers in settings that are understaffed (Kyakuwa, Hardon, & Goldstein, 2012).

Despite value in involving PHAs in HIV work, several challenges related to their meaningful involvement in HIV work have been identified. These include: lack of a legal framework to guide the inclusion of GIPA principles in policies and programs; a hostile social, cultural, and political environment towards PHAs; and a lack of training for PHAs and program managers on how to incorporate GIPA in organizations (Paxton, & Stephens, 2007; UNAIDS, 1999). The gap between GIPA ideals and practice demonstrates the complexities faced in incorporating GIPA principles. For instance, while PHAs have been extensively involved in research as participants, their input in the actual decision making processes is often minimal (Greene et al., 2009). HIV stigma, health related challenges, credentialism, and a lack of capacity to engage in specific work are often cited as the main obstacles to PHAs' participation in HIV work (Cain et al., 2014). Furthermore, the transition of HIV from a terminal to a chronic illness has reduced the visibility of the *need* for the inclusion of PHAs in HIV work (Cain & Todd, 2009). A lack of employment policies, inadequate remuneration, stigma, fear, and poverty have also been cited as major barriers to the active implementation of GIPA principles (NEPHAK, 2010).

Context of current study.

This research was carried out in a western Kenyan city in partnership with Utumishi, a large AIDS Service Organization (ASO). Utumishi provides HIV care and opportunities for PHAs to be involved in HIV work. Utumishi was formed in 2001 as a donor funded non-governmental organization in response to a high HIV mortality rate in a government hospital in western Kenya. The organization serves about 140,000 PHAs through its antiretroviral program and is spread across 20 satellite clinics in western Kenya. Utumishi incorporates HIV research, care, prevention, and community service and offers diverse services such as HIV testing and counselling, access to antiretroviral medications, legal and financial assistance, palliative care and nutritional programs.

Utumishi exists as a response to insufficient funding for the anti-retroviral (ARV) treatment program in Kenya. Being a low income country with a gross domestic product of $55 billion, Kenya is unable to support and comprehensively fund the HIV care needs of its citizens (World Bank, 2015). Furthermore, with 46% of the population living below the poverty line (earning under $2 a day) (World Bank, 2015), most of the PHAs cannot afford ARVs unaided. Donor funding accounts for 70% to 80% of the HIV dollars while the Kenyan government contributes 17% of the total HIV care budget (AVERT, 2014; NASCOP, 2012). Utumishi is the main employer of PHAs in western Kenya where about 81 PHAs work as frontline HIV care workers. The aim of this study was to explore how PHAs related to Utumishi as clients and employees and how they fulfilled the GIPA mandate through the stories they lived and told.

Theoretical Framework

Lindemann-Nelson's (2001) conceptualization of found and chosen communities informed my understanding of how the participants, as people living with HIV, story themselves or are storied based on their voluntary or involuntary associations in a society. In this study, I recognized that HIV care workers occupied diverse places within the ASO and the community, calling forth different narratives that helped me understand how participants were afforded or constrained in their opportunities to realize GIPA. Friedman (1995) describes membership in found communities as relatively involuntary and it occurs when membership is given or ascribed based on the physical and social positioning of an individual in the wider community. In found communities, dominant stories set the parameters for how members fit in, granting them a sense of identity, belonging, and entitlement (Lindemann-Nelson, 1995; Mcniff & Whitehead, 2000). Personal identity for members in found communities is dependent not only on the interaction with self, but also with others in the community, determining permissibility to exercise moral agency among members (Mcniff & Whitehead, 2000). Because dominant stories in the found community universalize experiences, ambiguity, ambivalence, oppression, and contradiction among members may be present (Friedman, 1995).

Lindemann-Nelson (1995) also advances the idea that not every person’s narrative conforms to the expectations or dominant stories of the found community. This reality necessitates the creation of a chosen community wherein members resist the dominant narratives by living and telling a counterstory. Counterstories may be those that run counter to the dominant narratives, marginal stories or those told by members who consider themselves outsiders (Andrews, 2004). Often, counterstories are told to expose moral ideas that dominant stories ignore (Lindemann-Nelson, 1995). By living a counterstory, the teller seeks acceptance, inclusion, correction, and restoration by inviting new or different interpretations and conclusions that are at odds with the ones that dominant narratives invite (Lindemann-Nelson, 1996).

Living a counterstory can repair damaged identities caused by the dominant narratives by revising and retelling the social-historic and cultural narratives that entrench the dominant narratives as the norm (Harter, Scott, Novak, Leeman & Morris 2006). Reclaiming lost and damaged identities becomes a possibility through social reengineering and telling counterstories (Lindemann-Nelson, 2001). Even within the found communities, counterstories can be lived and told by creating a moral space where members can come together, to “discern, construct, correct and celebrate a community story” (Lindemann-Nelson, 1995, p. 24).

Design and Methodology

I utilized narrative inquiry to inquire into the experiences of four PHAs who also worked as HIV care workers at Utumishi. Through listening, observing, living alongside, writing, and inquiring into the texts produced (Clandinin & Connelly, 2000), I hoped to understand how four participants made sense of their experiences living with HIV and how they realized the GIPA principles. Narrative inquiry rests on the assumption that human beings make sense of their lives and interpret them based on the societal stories available to them (Bruner, 1990). These societal stories are embedded within and embody the dominant cultural stories or meta-narratives of gender, sexuality, and social, economic, and class found in particular landscapes (Sonja, 2013; Ussher, 2006).

Clandinin and Connelly's (2000) metaphor of a three dimensional inquiry space helped me to think about how contextual, temporal, and social dimensions shaped the way PHAs lived and told their experiences, recognising that HIV stories are contextual stories (Caine, 2010) and lived in relationships (Liamputtong, 2013) that evolve over time (Pierret, 2007).

Before the study began, ethical review was acquired from the Institutional Ethics Review Board of the University of Alberta, Moi University, and organisational approval was received from the ASO. Inquiring into the experiences of PHAs providing HIV service, provided me with insight into how they story themselves as clients who receive care, while at the same time working as HIV care providers. Inquiring into their experiences also gave me insight into how institutional narratives shaped the way the participants lived and told their experiences. Over a period of 3 months, I engaged with four participants in 10 to 12 conversations each, spending time with them at work and in social places important to them. I wrote extensive field notes and made personal reflections throughout this time.

Over time, I began to comprehend the details of their life experiences, including pain, hopes, dreams, and beliefs (Bell, 2002; Coles, 1989). In addition, John, a senior PHA working within Utumishi as a departmental head, provided me with institutional insights about how PHAs related to the ASO. Having been with Utumishi from its inception, first as a client, and at the time of the study as a senior HIV care worker, John had an in-depth understanding of the history and the inner workings of the ASO that might have been different from the participants.

Narrative accounts, which reflect PHAs' lived and told stories and my relationships with them, were co-composed in relation to the research puzzle (a narrative term for research question). By rereading the narrative accounts, field notes, and the interim texts, I reflected on the emerging threads that cut across the individual narrative accounts (Clandinin & Caine, 2013; Clandinin & Connelly, 2000). These threads formed plots and subplots that made up the pieces of a larger story (Hill, 2011). I also listened to the audible and inaudible voices of the participants as they lived and told their HIV stories in the midst of, and in relation to, Utumishi. Pseudonyms are used to refer to participants and the organization.

Results

The four PHAs who were part of this study began as clients at Utumishi having been recruited into the HIV program soon after they tested positive for HIV. At the time of enrolment into the HIV program, their lives had been devastated by the physical and social effects of their HIV diagnosis. In part this may have been related to a sense of rejection, stigma, and other social consequences of their HIV diagnosis. Over time, the participants began to attend support group meetings where they learned to live and tell their experiences of living with HIV. Eventually they were deemed qualified to be hired as HIV care workers within the agency.

Living alongside PHAs, attending to their experiences of living with HIV, observing them at work and visiting with them in social places, I gained insights into their stories to live by, as PHAs and HIV lay workers . By living and telling their HIV stories, they communicated the ordinariness of an extraordinary past, as well as important landmarks that drastically changed their lives. Atoti, Nelly, Luanda, and Estero identified key moments that helped in forging and sustaining their HIV identity. These moments were: a) how they came to know their HIV status; b) being handed a lifeline; c) becoming community advocates, and d) fearing for their future.

Coming to Know Their HIV Status

Numerous factors motivated participants to want to know their HIV status. For some participants, it was by chance while for others it was by choice. For Atoti, it took two HIV tests to accept that she was living with HIV. She was initially tested in an antenatal clinic during her first pregnancy, but she dismissed the result as a false positive test. However, 4 years later, when the test was offered during her second pregnancy's antenatal visit and returned positive, Atoti chose to take it seriously:

> *In 2000, I went to the antenatal clinic and I was tested for HIV which came positive. At that time, I never took the diagnosis seriously because I took it as a false positive and I did not disclose to anyone. I later on delivered a baby boy and breastfed him. In 2004, I became expectant again and went to the antenatal clinic, retested and was found to be HIV positive. It was then that I decided to have my husband tested for HIV whose test returned negative. I was really shocked by the turn of events; that I was HIV positive and my husband was not, and felt as though my world was crushing beneath my feet.*

Curiosity drove Nelly to want to know her HIV status. After the birth of her first child, she suspected that her husband was unfaithful to her. Feeling threatened and exposed, Nelly went to the HIV testing centre to have her status checked. When the test came back positive, she was devastated because she had believed that as a married woman, she was immune to HIV infection.

> *Soon the birth of our first child, my husband became unfaithful to me. When I became expectant with my second born, I reasoned that I needed to know my status in order to protect my foetus if I was infected with the HIV virus. I secretly went for the test and the test turned positive for HIV antibodies. My body weakened due to the stress I was under. I was in denial because I never thought it could happen to me.*

For Estero, it was his wife's sickness that motivated him to know his HIV status. After his wife was diagnosed with TB and pneumonia, a suggestion was made by nurses working in HIV clinic that both Estero and his wife take an HIV test. After being tested, Estero had no time to respond to his HIV diagnosis as he needed to support his gravely ill wife.

> *My wife refused to be tested for HIV when she was pregnant as we were a bit afraid to test at that time. The delivery went on well but the baby got ill immediately and died after 8 months. In 2010, she became sickly and was diagnosed with TB and the HIV nurses encouraged us to get tested. We took the test and both of us were HIV positive. Although we tried to be positive so that my wife could accept to be put on treatment, inside me, the HIV diagnosis was eating me up. I could not sleep or eat.*

Luanda was also diagnosed in similar circumstances when he was taken to a hospital after developing meningitis. Although he could not recall being offered an HIV test, he remembered being told on discharge that he needed to be followed up in an HIV clinic.

> *I was admitted to a hospital with a sickness that affected my memory, and I was mentally ill. I was discharged a week later to go home and the doctor told me that according to my condition, I will be going to an HIV clinic. . . . I was not counselled. They may have tested [for the] HIV virus without telling me.*

Although being diagnosed with HIV was a traumatic moment, the aftermath was perhaps more devastating for each participant. In addition to social isolation, desertion, poverty, and loneliness, the social situations that the participants found themselves in aggravated the pain of the diagnosis. Nelly experienced such severe domestic violence from her husband that she contemplated suicide. Her marriage irreparably broke down, leading to her separation. Estero lost his job and his wife two months after their HIV diagnosis. As a result, he became socially isolated and disconnected from family and friends and was hence unable to meet the financial obligations of his family. Luanda's trauma of HIV diagnosis was aggravated by the way his diagnosis was communicated to him by his attending physician. He shared that he was too ill to consent to an HIV test and therefore he was not counseled. Furthermore, his wife deserted him as soon as he was admitted to the hospital. The pain of his wife's desertion, coupled with his HIV diagnosis, was so overwhelming that he turned to alcohol to deal with his pain. This impaired his economic productivity and his ability to adhere to antiretroviral medications. Atoti was demonized by her HIV negative husband the moment her HIV status was confirmed. Soon after her diagnosis, her husband deserted her, despite her being 6 months pregnant. Dejected, poor, and stigmatized, she resorted to sex work and the sale of illicit alcohol for her survival and that of her children.

Handing Them a Lifeline

The physical, mental, social, and economic vulnerability that resulted from the HIV diagnosis devastated the participants' sense of being. HIV shattered their self-image, identity, and esteem, and predisposed them to severe socioeconomic consequences. To change the course of their socioeconomic and physical downturn and to increase access to lifesaving medications, the provision of support to find meaning and purpose in life was paramount. Reaching out to Utumishi for help was crucial for all of the participants. Through diverse programs such as medical, legal, social, psychological, and counselling services, Utumishi was instrumental to the repair of their damaged identities.

The support groups run by PHAs at Utumishi provided participants with a sense of belonging, a place of networking, and created an environment where reciprocal love, respect, and recognition flourished. When Luanda attended his first support group meeting, he found the aura of Utumishi irresistible, and he kept on returning to meet with other PHAs. Self-acceptance that had eluded him for many years became possible and he managed to break away from the destructive habits of alcoholism and unsafe sex. Luanda's sense of belonging and loyalty became tied to Utumishi's role in transforming his life:

> *Were it not for Utumishi and the psychosocial department, I could be dead. It took me a long time to accept my status. That is why I used to come for clinic here rather than another place. Because here, the medications are free, we freely discuss with our members our concerns. At Utumishi, one has a sense of belonging, and because of what they did for me, I feel great associating myself with them. Utumishi was critical in helping me overcome my drinking habit and that is why for me, I want to make a difference in people's lives as much as possible. Working here is like a calling.*

To Atoti, Utumishi was her second "God." This was a metaphorical expression to demonstrate how Utumishi had transformed her and continued to do so. Atoti believed that due to Utumishi's assistance, she was even healthier than she had been prior to becoming HIV positive:

> *You know that Utumishi was created to cater for people living with HIV. It is concerned with our holistic welfare such as the medication supply, treatment, social worker and other welfare issues such as housing, school fees etc. To me Utumishi is my second god. By giving me a chance to live, my children and those of people living with HIV are not orphaned. My life is restored to what I was even better than when I was HIV negative. My strength is now back and as a result, [I] have committed to working for my clients that are living with HIV.*

At Utumishi, the participants met other PHAs, developed relationships with them, and honed their public speaking and relational skills. Subsequently, over time, the participants became expert HIV educators and support group facilitators. In addition to the medical and social help that PHAs received to rebuild their lives, they were hired as HIV lay workers by Utumishi. Their experiences living with HIV were deemed valuable assets. They supported HIV clients as they accessed services, and navigated the system. In addition, the participants counselled, educated, and facilitated support group meetings. The socioeconomic benefits of working for Utumishi were most important:

> *Getting a job here is significant because it has supported me and my children; it has helped me pay for my education and that of my children. Also, being in Utumishi allows me to access free treatment which is a great relief. Many people who were diagnosed with HIV at the same time have already died. At that time, ARVs were very expensive and I could not afford them. If I needed the meds at that time, I am sure I would have died, since I could not afford them. Luckily when I needed them, Utumishi was providing them for free to as many people who required it. (Nelly)*

Estero had been jobless for the 2 years prior to the research. Utumishi's offer to Estero of a research assistant position was a lifeline that allowed him to break his isolation and relocate to the city where he reconnected with friends and met his financial obligation to his family. For Luanda, following his HIV diagnosis he was unable to resume his work as a tour and travel agent. He did menial jobs to support himself until he was offered a job by Utumishi as a lay health worker. This allowed him to reclaim his identity.

When Atoti was hired at Utumishi, she stopped working as a sex worker and selling illicit brew. The new job enabled her to assume and embrace a new identity and a new lifestyle. After Atoti was hired at Utumishi as a psychosocial worker, she gave birth to three more children. All of her children were HIV negative, in part due to the prevention of maternal to child transmission of HIV (PMTCT) services offered at Utumishi. This gave her immense joy and also made her feel "normal" once again. Over time, Atoti regained her self-esteem, belief, and determination. As a 38-year-old mother of six, she completed her high school education and bought land where she built a home. To her, HIV stories were no longer afforded more importance than her struggles with poverty, parenting, and other social issues. Rather, her HIV infection became an opportunity and a "door opener" for her personal, social, and economic growth. Ironically, Atoti wished that a cure for HIV would be delayed so that she could continue to tap into the opportunities that her disease provided:

> *Even now, my prayer is that the cure for HIV should take a little longer before it is discovered. (Laughing). . . If a cure is found, we will be out of work. This disease has taken care of us.*

Although Nelly had sworn never to remarry after her experiences with her first husband, she told me that with time and the support of the network, her self-esteem and self-belief had grown to a point that she began to reconsider remarrying. When she met George, also a PHA, she did not hesitate to marry him. She has since rekindled the joy of being a mother and a spouse. Nelly also reenrolled in school and received a high school diploma and at the time of our conversations was pursuing a diploma in counselling:

> *I sat for high school diploma in 2011 as I had the desire to pursue education, but opportunities were not there for me (since my parents could not afford school fees). Since then, I have attended many counselling and HIV related short courses while working at Utumishi. Now I am taking [a] certificate in counselling. I have taken trauma counselling as well and I have immense experience in counselling.*

Estero was glad that working for Utumishi had helped to shift him to a path of social, personal, and economic growth. Although he still struggled with poverty and accepting his HIV status, he began seeing himself as someone with a bright future. He hoped to become an HIV educator, counselor, or a clergy.

> *Actually, I am not even worried (after the contract is up) because as I have told you earlier, I am focused in life and know what I want. I want to take the gospel out, using my powerful HIV testimony. With the little experience and training that I have gotten, I feel empowered by Utumishi to be effective in what I plan to do. I have narrowed down my options into what I want to be. I want to be a pastor of a church and if it will not work, I wish to play a very big leadership role in the church especially to assist the people either affected or infected with HIV.*

Luanda had remarried and was a father to a 2-year-old girl. He enrolled in a degree in counselling, and re-storied himself from an alcoholic and a risk taker to a man taking responsibility for his future. His ultimate mission was to pursue advanced studies in counselling:

> *What gives me meaning in life is the job I am doing now as a psychosocial support worker. I graduated with a higher diploma in counselling and psychology last December. I intend to do my degree as soon as I get resources and hope to do [a] PhD as well.*

Becoming Community HIV Advocates

Participants' experiences of being clients and workers at Utumishi, and the transformation they experienced by associating with the organization, positioned them to be HIV change agents who engaged others on HIV matters. The realization that Utumishi afforded them free medical care and other support services was an impetus for the participants to engage in actions that demonstrated social responsibility. They felt duty-bound to respond with compassion and tenderness to those not yet diagnosed with HIV or those who were struggling with self-acceptance of their HIV status. They also realized how privileged they were to be working with Utumishi, an association that had helped to lift them from poverty. Furthermore, with their restored self-esteem, they were comfortable to engage in HIV work in the community.

The experiences of living with HIV significantly shaped how participants approached their work as HIV lay workers . Although they were not officially required to disclose their HIV status to others, participants found it necessary to do so in order to support those who were in crisis. Nelly was passionate about working with HIV-positive children or parents living with HIV who had young children. Having experienced being a single mother living with HIV herself, she believed that she was able to empathize with them. Drawing from her personal experiences, she supported clients to obtain necessary resources:

> *As a PHA, I understand the feelings clients have, because I passed through the pain of testing and subsequent anguish. I am able to empathize with them, to help them accept*

> *their disease and live positively. As a young mother with three children, I know what it feels [like] to live with HIV. Acceptance is what they need, because some are orphans, who acquired HIV through non sexual means. It is thus our responsibility to make them live normal lives as well.*

Nelly also supported parents to apply for scholarships, bursaries, and financial support for their HIV positive children.

Luanda had struggled with adherence to ARV medications due to denial and alcoholism, leading to resistance to first line ARV treatment. As a result he understood the complexities of adhering to ARV medications and clinical appointments. At Utumishi, he rescheduled clients who missed their appointments. For him, performing HIV work required personal sacrifice and loyalty to clients:

> *This work we do involves dealing with male and female clients. So a female client might call me after hours. I normally say help extends past office hours. So sometimes my wife does not understand why I receive calls from clients during the off hours. I am committed to my work; [I] wake up early to be in the office at 7 am. To me working here at Utumishi is like a calling because [of] what I underwent before I stabilized, I would not want anyone to go through that. So I am too committed to my job. I try to balance with family as I know that I have a family to feed.*

As a research assistant, Estero enrolled PHAs who were new to ARV medications and who had experienced adverse side effects such as a rash, itching, and diarrhoea. Many of the clients in this study had questions related to their HIV status and their ARV medications. Estero and his colleagues counselled them on the importance of adherence to ARV medication, and particularly on the prevention of HIV transmission between discordant couples. By sharing their personal experiences, the PHA participants made their encounter with the clients lively and relevant.

In the community, outside of Utumishi, participants became HIV educators, resource persons, consultants, and liaisons to Utumishi. Estero was an HIV educator whenever he travelled to his rural home. There he taught community workers about the latest medications and distributed HIV related materials to support his education sessions. Over time, people in his rural community had come to depend on him to update them with new HIV information. Through selective disclosure, Atoti pursued people in the community who were exhibiting signs of HIV infection. She mobilized the Utumishi outreach team to take the unwell community member to the ASO for HIV testing and support. Luanda spent much of his free time in the community talking about HIV. He told me that although his involvement with HIV work was at the expense of family time, spending weekends giving HIV talks in schools and colleges, provided him with a great deal of fulfillment. His sense of obligation to the community helped to establish community-based organizations to address stigma.

> *I am a founding member and [current] member of the technical committee of Network of Christians with HIV. When we first launched it, I shared my HIV story with the church. They were all quiet as I shared the reality of HIV. Even in churches, we have people who are struggling with disclosure and we give them support. I am told some churches still discriminate against people with HIV but church C embraces you because they know you are either infected or affected.*

Fearing for Their Future

As my relationship with participants grew, I sensed that although the participants were glad to be associated with Utumishi, the uncertainty that surrounded their job security as HIV lay workers was worrisome. This fear was confirmed by the insights provided by John. Luanda openly shared with me his concerns about losing his employment, having witnessed some of his colleagues receiving letters of termination or failing to have their contract renewed. Apart from the potential loss of their livelihood, Luanda felt that a termination of his work would adversely affect the identity that he had come to embrace related to his association with the ASO. Having benefitted so much from his association with Utumishi, and feeling like he owed his life to the ASO, Luanda could not comprehend a future without this association. He reluctantly pursued an advanced degree so that he could be employable should he lose his job.

> *Although I know my colleagues are being laid off at Utumishi, I am not worried. I am sure with my education now; I can easily secure a teaching or counselling job in this town.*

In addition to the four participants, John, a senior PHA in the ASO, provided me with several insights into the relationship between Utumishi and the HIV lay workers . He told me that since the workers were hired on yearly contracts, they lacked upward mobility beyond the position of a supervisor. He also told me that PHAs were not given preferential treatment in the jobs that they were professionally qualified for.

> *We have different cadres within the program and any psychosocial worker, who works well, has a chance of becoming a supervisor. However, by GIPA principles and by equity principles, there should be a rule that a certain percentage of positions at different cadres should be occupied by PHAs which is not the case. So it is like they are trapped in the psychosocial support and retention department within Utumishi and they have no hope to ascend to other departments.*

In addition to a lack of upward mobility for many PHAs in the agency, John told me that PHAs lacked adequate representation in the management of the organization. Although participants never expressed this concern to me during our conversations, I wondered if they were aware of the GIPA principles or whether they felt it was important to be represented at managerial levels. John felt that PHAs' sense of belonging was under threat because no one had articulated their needs to the ASO's management board:

> *It reflects the extent to which GIPA is quasi assimilated in the program. Because what you would expect, is that somebody who is HIV positive to be in the decision-making organ. Like when they are deciding on such, who was on [the] board because each institution has a board as far as I know, there is no one that is HIV positive that is in Utumishi board. When they make those decisions, there is no one to advocate for any PHAs in the board. Therefore, their fate is hanging on the balance and the people who make decisions do not know what the PHAs are going through.*

While Luanda was forthright about his observation regarding the ASO, I also wondered what the other participants felt about their future with the organization. Did Nelly and Atoti, who had completed their high school diploma a couple of years previously, experience the same fear? Were they preparing for an eventual exit? I also wondered if the ASO had made PHAs dependent on the organization, rather than empowering them to be successful outside of Utumishi. Did the participants feel as though they had outlived their purpose?

Discussion

HIV diagnosis marked a beginning point in participants' journeys of internalization of an HIV identity. Diverse turning points that followed determined the extent to which the incorporation of an HIV identity was enhanced. Utumishi was key to the realization of these turning points, providing a platform for socialization and networking, as well as free medical and financial resources. Participants' immersion in HIV work increased their comfort and knowledge that was key to the incorporation of HIV identity into their lives.

The concept of found and chosen community proposed by Lindemann-Nelson (1995) helped me to think about how participant's positioning informed the ways they storied themselves and were storied. It also helped me to think about how the institutional and personal positioning of the participants contributed to GIPA activities within and outside of Utumishi. It was evident from our conversations that participants' membership in the found community was through their association with Utumishi as clients and HIV lay workers . The stories they told of themselves and Utumishi were shaped by the personal, contextual, and institutional narratives in which they lived, and provided a basis for which their sense of belonging and purpose was realized.

Initially and out of necessity, as newly diagnosed PHAs, participants enrolled in the antiretroviral medication program at Utumishi. At that time, their lives were devastated by the social consequences of HIV infection which included HIV stigma and discrimination, family breakdown, poverty, loss of esteem, and often a loss of livelihood. They credited Utumishi with helping them to repair their damaged identities and to reverse and mitigate the social consequences of HIV infection. The use of metaphors such as a "second god" by one participant gave deeper insights into the perceived redemptive role that Utumishi played in their lives, and represented a way to acknowledge the power and influence of the ASO in transforming their lives. To me, the expression of adoration to the ASO in this manner raised questions about the moral and ethical imperatives at work in their relationships with the ASO. I wondered how they objectively performed their work without feeling pressure to impress the ASO that they were sentimentally attached to it. Did they feel pressured to reciprocate the ASO's assistance in their lives, over and beyond their work obligations?

Participating in support group meetings and adhering to ARV treatment had a positive effect on participants, helping them to address personal vulnerabilities and live positively with HIV. Thereafter, they seized the opportunities to work as HIV lay workers within the agency which allowed them to live a decent life and to contribute to the welfare of other PHAs. Participants' experiential and practical HIV knowledge acted as a repertoire of guidance and support for clients within the agency (Kim, Kalibala, Neema, Lukwago, Weiss, 2012). Involving the participants in this way is consistent with the GIPA principle that encourages PHAs to be actively involved in HIV work (Paterson, Ross, Gaudet, 2014; UNAIDS, 2007). Their employment also gave participants authority to advocate for HIV clients and to support them to access resources they needed. As a result of their employment, the visibility of the participants' role as HIV educators and advocates was heightened, facilitating the fulfilment of the GIPA principles (Paterson et al., 2014).

No academic credentials were tied to the position of a lay health worker. This implied that those without high school education, such as Nelly and Atoti, had the same opportunity as Luanda who had several academic certificates. As I listened to the participants, I began to wonder if the lack of academic requirements to become a lay health worker may have diminished the prestige of the job. This in turn may have shaped the terms of service and extent of institutional influence and voice within the ASO. The lack of credentials has been cited as an obstacle to PHAs involvement in HIV work (Travers et al., 2008), and in the current study, the lack of credential consideration may have devalued the lay health worker position and their significance to the larger institution.

Utumishi provided the participants with a sense of entitlement and identity, yet, the ASO's acceptance of PHAs had its limits. HIV lay workers were unable to contribute to the day-to-day running of the organization and therefore PHAs were not represented at the decision making level as proposed by the GIPA principles (UNAIDS, 1999). In addition, lay health worker positions were temporary and the lowest in the organization. In addition, these positions were characterized by regular layoffs. The regular layoff of PHAs who, despite making a critical contribution to the ASO, raised questions about the institutional commitment to the GIPA principles.

The complex relationship between the ASO (as HIV care provider and employer) and the PHAs (as HIV clients and employees) highlighted the difficulties of translating GIPA ideals to practice (Travers et al., 2008). The personal and social benefits of involving PHAs as HIV lay workers were apparent, often leading to their socioeconomic emancipation and contributing to a sense of belonging. However, there was limited evidence of a genuine power redistribution within the ASO (Roy & Cain, 2001) as manifested by inclusion and upward mobility for PHAs.

Outside Utumishi in their respective communities, participants felt responsible to be a voice for weak and struggling PHAs. Propelled by a sense of moral and social responsibility, and utilizing skills, knowledge, expertise, and experiences learned from being clients and HIV lay workers , participants volunteered as HIV educators, liaisons, and community resource persons. Estero regularly provided free HIV education sessions for a community based organization and supplied others with current HIV literature. Luanda co-founded several community based programs to address HIV stigma among men. Through living and telling his own HIV story, Luanda provided HIV education to schools, colleges, and churches at the expense of his family time. Atoti became an active liaison person between the community and Utumishi, recruiting those she suspected to be infected with HIV. She also made supportive follow-up visits to PHAs struggling with accepting their HIV status and adhering to their ARV medications.

Through engagement with HIV community work, PHAs felt liberated to work without institutional restrictions. In these moments they worked within their chosen communities, exhibiting their individual agency and responsiveness to act with compassion for those infected and affected with HIV, in line with the spirit of GIPA (Ontario AIDS Network, 2011). HIV activism by PHAs within their respective communities not only redefined and expanded the usefulness of PHAs, but also challenged the institutionalization of GIPA by recognizing HIV work as meaningful outside an institution.

The participants reconnected GIPA to the grassroots, legitimatizing it through their HIV work with communities as a way to make a difference to PHAs. In so doing, they lived and told a counterstories which allowed them to resist the notion that their passion and involvement in HIV work was only motivated by material gain, recognition, or only within formal institutional settings. By forging their own paradigms and perspectives as HIV educators, liaison workers, and co-founders of organizations, PHAs invited a different interpretation of what it entailed to be meaningfully involved in HIV work, especially at the grassroots level.

Conclusion

Lindemann-Nelson’s work on found and chosen communities helped me to shape and understand the participants’ narratives, experiences, and expressions. This was an appropriate concept to give voice and expression to the complexities that characterized participants’ involvement in HIV work as clients, HIV lay workers , and members of the community. By delineating the participants’ experiences of being members of two distinct communities, diverse involvement in HIV work became more explicit.

In this study I inquired into the experiences of four PHAs involved in lay health work. While the results of this study are by no means generalizable, they serve to advance the understanding of diverse ways that PHAs fulfill GIPA principles. It was apparent that the participants lived and told dominant and counterstories. To live dominant narratives within their found community, they portrayed Utumishi programs as successful; their involvement as a way to celebrate its impact on their lives and also to encourage the clients they served. Living counterstories of who they became in their communities demonstrated their innovativeness and individual initiative in responding to the HIV needs of their community members. In the process of telling and living counterstories, they demystified HIV diagnosis and disclosure, as well as minimized HIV stigma.

Using the conceptualization of found and chosen communities, dominant and counterstories have helped me to understand the diversity in PHAs' involvement in HIV work. The dynamics of paid and unpaid HIV work and the meaning that the participants derived from HIV work became apparent as I lived alongside them. The realization of the GIPA principles requires that PHAs enjoy political goodwill and meaningful institutional involvement.

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Chapter 10: Reflections on the Process of Engaging with Individuals Living with HIV

In this research, through attending to the HIV stories that four participants in Kenya lived and told, living alongside them at work and in social places, I began to comprehend how they composed and negotiated their multiple identities. As our relationship unfolded, it became apparent that participants' lives were informed by internal and external factors, including personal and institutional ones. Moreover, in living and telling their HIV stories, an avenue was created for difficult, deep, and traumatic experiences to be shared. Some of these stories were told for the first time, which inadvertently unearthed raw emotions that had been previously unexplored. The participants called forth emotionally charged memories of a broken and traumatic past and at times, I did not know how to respond to. Although participants endeavored to integrate HIV into their lives, unresolved trauma resulting from social factors such as HIV stigma was a common impediment. Personal, social, and financial struggles also significantly influenced the integration of HIV into their identities and their lives.

After concluding my research engagement with the participants, I again met with John, a PHA who had introduced me to the participants. I had questions regarding some issues the participants had raised that required a deeper insight or clarification from him. Having been part of Utumishi from its inception, first as a patient and then as a founding member, John possessed historical insights and institutional narratives of Utumishi. In some way, John's HIV infection inspired the formation of Utumishi. He told me that as a patient dying of HIV complications, his attending physician reached out to his international colleagues and asked them to donate antiretroviral medications. He did this out of compassion to save John's life. As the first recipient of antiretroviral medications in Kenya, John's miraculous recovery brought hope and optimism that HIV mortality could be averted if antiretroviral medications were made available. Utumishi started with these humble beginnings and at the time of the research, it had provided antiretroviral medications to about 140,000 people living with HIV.

John told me that at the inception of Utumishi, the input of people living with HIV and AIDS (PHAs) was valued and treasured, and informed the operations of the ASO in congruence with the Greater Involvement of People living with HIV and AIDS (GIPA) principles. However, over time, the professionalization of Utumishi gradually relegated PHAs to the periphery and they were no longer represented at the decision-making level. No explanation was given for this glaring omission, but as a donor funded agency, John believed that Utumishi's main accountability and obligation was to its funders. As I listened to him talk about the philosophy that informed Utumishi operations, I wondered if the donors were committed to the GIPA principles. I also wondered about the relevancy of GIPA principles in an ASO such as Utumishi where PHAs had no rights, claim, or stake in the organization. Interacting with John deepened my understanding of the personal, social, and practical implications of my research.

From this research, it was apparent that HIV identities were fluid and were negotiated, silenced, and enhanced, depending on the role and the locations that participants played and inhabited. HIV identity construction was foregrounded in pre-HIV experiences, and anchored in current and anticipated HIV experiences. Interestingly, HIV identity was more salient within Utumishi where participants worked as HIV lay workers, reflecting public expectations and the demand of their jobs. As HIV lay workers, HIV identity was lived out as an educative, informative, and supportive endeavor. It is within Utumishi that participants felt comfortable and safe to exhibit and live out their HIV identity.

There was a variation in the degree to which HIV identity was incorporated in participants' lives. In public, Nelly used her HIV experiences to encourage and support other HIV clients. However, in private, she continually agonized and mourned her HIV identity as her greatest tragedy. Through her experiences, I was persuaded that her HIV identity was a work in progress. Estero too struggled with his HIV identity, and took great pains to hide his HIV status including not pursuing close social relationships with family and friends. While Atoti presented herself as a confident communicator of HIV issues, her discomfort in living her HIV identity outside of Utumishi (which was her safe space) was evidenced by her warning to her audience not to identify her as HIV positive outside of Utumishi.

Outside of Utumishi, in private and in social places, HIV identity was overshadowed by other identities and roles that the participants played. At the beginning of our conversations, participants had impressed on me that HIV was their most significant identity, defining who they were and who they were becoming. However, the passage of time and a close relationship with participants challenged this assertion. Their experiences of being a mother, father, and spouse were given precedence in private conversations. This raised the question of whether HIV was an identity that was carefully negotiated and pursued to serve participants' interests. I also wondered what constituted their HIV identity.

Personal Implications

As a beginning inquirer, I was vaguely aware that by inquiring into the experiences of people living with HIV, I was engaging in potentially sensitive research, the results of which I was unprepared for. My initial anxieties revolved around my discomfort in asking potentially sensitive questions and the possibility that participants might be unwilling to engage with me relationally. My fears were nevertheless quelled and I easily settled into the research, aided by my willingness to adapt to the situations. Further, the eagerness of the participants to tell their stories made our bonding easier than I had anticipated. I was offered their unedited life accounts, some of which were almost too difficult to describe. In hearing these stories, I often became emotionally distraught and experienced guilt when I heard what the participants had gone through after they were diagnosed with HIV. My commitment to know participants in their milieu created numerous opportunities for us to experience shared vulnerabilities. Rather than holding onto my researcher identity, by demonstrating trustworthiness, fidelity, patience, and respect, I became an active participant in the inquiry. In time, I earned their trust and never raised objections about the appropriateness and relevancy of the stories that were shared with me.

I realized that many of the stories that were shared with me were told for the first time; I was very honored by this privilege. These initial narratives, which were often traumatic and emotionally charged, allowed me to bear witness to their brokenness and somehow enter into their emotional spheres and imagine, alongside them, what life had been like since they were diagnosed with HIV. Nelly's moving stories about being infected by her unfaithful husband and being subjected to intolerable violence and attempted murder by him, stayed with me for a long time. Atoti also told difficult stories of being abandoned by her family and the community when they learned of her HIV status. With no way to support herself, she engaged in prostitution and sold illicit beer. Atoti told even more traumatic stories, a majority of which she asked me to keep secret.

Because of my sustained engagement with the stories participants lived and told, I feared that I was becoming emotionally involved in their experiences in ways I had not imagined. My respect for the participants grew as they lived and told of these experiences. Despite the trauma associated with telling, I felt that through living and telling these stories, participants were trying to take charge of their lives by confronting the pain, fears, anxieties, and uncertainties that HIV had caused them. I knew we were jointly transformed in the midst when:

> they no longer hid their brokenness, hurt and trauma
> they no longer wore a façade to impress
> they did not care what and how they told their stories
> they told a 'bad' story instead
> I felt overwhelmed by the details of the stories they shared
> I was asked to be a confidant of the stories they lived and told
> I was told I was the first to hear some stories
> I was morally and ethically challenged
> I did not have a response when called upon!

Although I came into the inquiry as a researcher, knowing the participants intimately through the stories they lived and told made me a more respectful, empathetic, and sensitive researcher. I engaged not just my ears, but my mind and soul with their telling. Lugones' (1987) metaphor of *"world travelling"* helped me to reflect on my journey of engaging participants in a relational way. Lugones (1987) used the phrase *world travelling* to describe her engagement with people who were ethno-culturally and linguistically different from her. To Lugones (1987), for something to be a *world*, it has to be inhabited by real or imaginary people, of any kindred, race, or culture. A world would also constitute a segment or a larger section of a society; individuals who may not understand or hold a particular construction of themselves in that world (Lugones, 1987). To travel to and inhabit is therefore an engagement with people with contrasting particularities to those of the traveler (Lugones, 1987).

In thinking with Lugones' (1987) concept of world travelling, I was aware that I entered the research landscape from a position of 'privilege'; a graduate student at an overseas university, bearing academic, material, and social capital and not burdened by HIV stigma and other consequences of HIV infection. The participants, on the other hand, primarily occupied a world that centered on HIV where in public they lived and told HIV narratives that were consistent with their roles as HIV lay workers. However, in private, they lived different kinds of stories.

As I world traveled with my participants, I realized that their lives were strange and unfamiliar to me and that they made me uncomfortable at times. Yet, this engagement was necessary to understand their experiences as PHAs, especially in their social milieu. At the beginning of this inquiry, I was burdened by a sense of “privilege” that hindered my ability to connect with participants. In order to make authentic and meaningful connections with the participants, I had to learn to travel both physically and emotionally to their world. Some worlds were real, while others were constructed in my imagination. Hence, I often found myself departing from the familiar to the unfamiliar, which was accompanied by my willingness to question my identity as a researcher. In so doing, I got emotionally engaged in their worlds and in what Lugones (1987) calls playfulness. Although travelling to the participants’ worlds was emotionally intensive and exhaustive, it was immensely rewarding and transforming, allowing me access to those experiences that were unavailable to me previously.

In travelling to Luanda’s world for instance, he led me to places that were unknown to me which, although terrifying, held great significance to his stories to live by. These included his home and social places where we shared social moments together. Subsequently, I became wakeful to the realities Luanda lived in his private life. I also understood that inhabiting certain places called forth experiences and stories that reflected who Luanda was and who he wished to be. With Estero, gaining access to his physical space where he lived a lonely and secluded life, brought unparalleled insight into how he composed his life in order to conceal his HIV identity. Although I had learned earlier that he struggled with disclosing his HIV status to others, it was while visiting him at home that I was confronted with the pain, loneliness, and anguish that his inability to publicly live out his HIV identity brought. Moreover, it was during this visit that he opened up his life in an unprecedented way, showing me photos of his wife's funeral. Watching these photos was emotionally distressing to Estero, as it reminded him of the demise of his wife. Yet, it also allowed him to celebrate her life.

My reluctance to engage with female PHAs as participants in this research was informed by the fear of being misunderstood and misrepresented while in their midst. In overcoming my own fears and discomfort, together we visited places of social significance to them. I was rewarded by the generosity of their relationship with me. Although I never understood why some stories were told to me, I persevered and endured as the difficult to tell stories were lived and told. In attending to the complexities of their lives in this manner and sharing in their vulnerability, there were unintentional results, leading to personal and relational transformation and growth. Together we confronted our fears, anxieties, and uncertainties. In so doing, other opportunities to explore our lives deeply were made available. No longer was I a bystander in the inquiry and instead became an active participant, inquiring into my own life and allowing my assumptions and attitudes to be challenged. I became even more uncertain of who I was becoming as our relationship developed. Was I a researcher, a friend, and a confidant? I certainly felt that the more I knew my participants, the more I became empathetic, caring, humble, and humane.

Practical Implications

"As we care for patients and their families, we listen to their stories.
We also share our practice in the stories we tell.
Telling stories and listening to those of others underscore the similarities and connections among us." (Carroll, 2010, p. 235)

My eagerness to inquire into the experiences of living with HIV began at a medical unit in a Kenyan hospital where I cared for Solomon, a person living with HIV who was confined to his deathbed. Thereafter, this curiosity took me to diverse places where my perspective of who people living with HIV were and were becoming was significantly challenged and shaped. In particular, in coming to Canada, my understanding of the roles that PHAs played in HIV work shifted. Fundamentally, I understood that their experiences of living with HIV were fundamental to communicating the reality of living with HIV. In living and telling of experiences, programs have been inspired and sustained using the GIPA framework. Through PHAs' telling, health care providers have been mentored and taught about what it is to live with HIV.

Returning to Kenya to undertake research for my doctoral work provided me with an opportunity to explore how Kenyan PHAs' experiences of living with HIV could inform policy, programming, and practice. Looking back at my own experience inquiring into the stories of four participants who lived with HIV, I recognized that their stories were a powerful tool that had the potential to enrich HIV care, education, and policy development. Considering the power of stories as agents that can inform practice, I was drawn to Downey and Clandinin's (2013) writing on narrative reflective practice. They took up Dewey's (1934) work on experiences and were persuaded that narratives could drive change in education and practice. In reflecting on experiences, which, to Dewey were continuous and interactive, Downey and Clandinin (2013) argued that a connection between action and consequences becomes possible. In addition, in attending to the experiences of living, it becomes an educative practice with a potential for growth and change to both the teller and the inquirer. In narrative reflective practice, an inquirer can thus reflectively consider the implication of stories lived and told and how these can inform their practice (Craig, 2009).

The stories participants lived and told in this research have major implications for HIV care. Participants storied themselves as recipients of care at diverse points of their lives. They also told how the interactions with the health care providers impacted in their HIV identity. For instance, when Atoti shared her experiences with Jane, an HIV nurse she met when her son was admitted to hospital, Jane believed and acted on her experiences. Thereafter, Jane approached the unit's social worker and successfully advocated for Atoti's medical bills to be waived. Thus, Jane became an agent, through which Atoti's life was transformed, supporting Atoti's lifestyle change from a commercial sex worker to a small businesswoman. Subsequently, with the support of others, Atoti embraced her HIV identity and freely shared her HIV stories with others. In contrast, Luanda's unprofessional and unethical treatment by the attending physician led to his loss of trust in the health care system. The physician, without consent, tested Luanda for HIV when he was admitted with meningitis. Luanda thereafter struggled with adherence to treatment regimens.

In considering Atoti and Luanda's experiences in care, it was apparent that the patient-health care provider interaction has a significant bearing on clients' health related decisions and choices. The difference between Luanda and Atoti's experiences in care was perhaps based on health care providers' willingness to attend to and value clients' experiences. It is therefore imperative that health care providers attend to the experiences that their clients bring in order to provide culturally sensitive care, to deepen an understanding about them, and to be more tolerant towards them (Carroll, 2010). In vouching for a need for providers to attend to clients' experiences, Last (2012) encourages practitioners to engage in narrative medicine. This requires practitioners to make a deliberate attempt to attend to and incorporate patient stories and experiences as a basis for their decisions. This approach provides a platform for clients to live and tell their experiences of living with an illness, and creates possibilities for providing individualized, holistic, and patient-centered care (Hall & Powell, 2011). By engaging in narrative medicine, experiential knowledge is acknowledged and legitimatized. Cooke (2002), in recognizing patients as experts in their own illness, notes that "patients inevitably have knowledge that health professionals simply cannot possess, both of the circumstances of their individual lives and how *the* system is working, or not, to enable them to manage or mitigate them" (p. i68).

Clients' stories also have the potential to transform care providers by invoking moral and ethical imperatives for the caregiver (Coles, 1989). Coles observed that;

> stories are renderings of life; they cannot only keep us company, but admonish us, point us in new directions, or give us the courage to stay a given course. They can offer us other eyes through which we might see, ears in which we can make soundings. (pp. 159-160).

Therefore, as a serious enterprise, listening to and telling stories shapes both the teller and the listener (Spiegel & Charon, 2004), and demands a shift from thinking *about* stories and treating stories as mere objects, to thinking *with* stories (Frank, 2004). To Frank, thinking *with* stories is a process that allows a storied experience to work on the inquirer to understand what they represent. It is also a way to foster change (Morris, 2001). Clandinin and colleagues (2011) assert that to think *with* stories is to think relationally, by calling forth social, institutional, familial, and linguistic narratives in which stories are embedded. To think *with* stories, personal immersion and sedimentation of narratives (Frank, 2004) arising from a relational commitment is key if an inquirer is committed to knowing and feeling for others (Spiegel & Charon, 2004).

Having been greatly impacted by the narratives of my participants, I began to imagine for a moment, how different my care to Solomon would have been had I come alongside him as I did with my research participants. I recognized that active listening, engaging in empathetic practice, and learning from clients what it is to be sick and to bear the burden of an illness is critical and needed. I concur with Benner and colleagues (2008) observation that the nurses' main responsibility is to meet the needs of clients, by comforting and empowering them in their moments of vulnerability. I too realized that sympathetic care is enacted as a response to the pain and suffering of patients that care providers' witness (Schultz & Carnevale, 1996; Naef, 2006; Kazanowski, Perrin, Potter, & Sheehan, 2007). It is in bearing witness to a patient's illness experience, that a practitioner experiences an ethical response, which is a human way of being and a fundamental part of nursing practice. Bearing witness also entails being there and being with, listening and attending to the patient as they experience an illness and to be "fully engaged in other's situation of illness, and hence, to be faithful to what he or she suffers – is to suffer the presence of the other's affliction" (Schultz & Carnevale, 1996, p. 197). As a witness to, and in being present with, the telling of the participants, I too recognized the transforming power of narratives that drew me closer to their experiences.

Social Implications

HIV as a chronic illness was a prominent narrative that was lived out by the participants, all of whom were taking antiretroviral medications. In their telling, participants were certain of a life expectancy comparable to that of the general population as long as they adhered to the treatment regimens. By adhering to antiretroviral medications, HIV became invisible on their bodies. Subsequently, participants felt enabled to undertake self-improvement activities such as completing schooling, bearing more children, and making investments. While participants were glad that their bodies looked “normal” in every sense, the invisible social consequences of HIV remained and continued to shape their lives in significant ways.

To begin with, all of the participants had struggled with stigma, low self-esteem, and denial resulting from HIV infection. HIV stigma in particular, had wide reaching consequences that had impacted their ability to integrate HIV identity into their lives. Furthermore, the emotional scars of HIV infection had stagnated some PHAs’ efforts to make significant progress in personal and social aspects of their lives. For example, soon after Estero was diagnosed with HIV, he relocated to his rural home where he lived in seclusion for 2 years. Although this seclusion helped him conceal his HIV identity, it deprived him of an opportunity to receive social support to deal with the consequences of HIV infection. Even after returning to the city, he continued to live in seclusion, fearful of being identified as one living with HIV. Furthermore, although he longed to remarry, after the death of his wife he was unable to restore his family identity through marriage. He feared being rejected by partners when they learned of his HIV status. So strong was the fear of HIV stigma that he had not disclosed his HIV status to anyone outside of Utumishi where he worked as a research assistant. Nelly too was forever haunted by the memories of domestic violence, rejection, and near homicide by a partner who she blamed for infecting her with HIV. Although these events happened 11 years previously, they continued to shape who she was becoming. Although she had since remarried, she still struggled to reconcile her HIV status with her other identities. By reliving her sense of victimization by HIV infection, her self-acceptance and a full embracement of her HIV status had been greatly hampered.

For Atoti and Luanda, financial difficulties were the invisible social issues that shaped their HIV experiences. Atoti was heavily burdened by the care of nine children, three of whom were HIV orphans. As the sole bread earner, she was traumatized by the chronic financial situation she found herself in. Although Luanda portrayed an image of an accomplished HIV educator at Utumishi, his inability to provide for his family's necessities of life was a major concern.

From this research, it was apparent that although participants were physically "normal" their overall wellbeing was far from secure. The invisible psychosocial and socioeconomic issues evidently hampered the incorporation of their HIV identities into their lives in significant ways. It is therefore imperative that, in addition to having access to life-saving antiretroviral medications, PHAs must also have access to social services to support positive living and to enable them to embrace their HIV identity.

In living and telling narratives of HIV as a chronic illness, participants assumed more responsibilities in their self-care and behavioral modifications to positively cope with the illness (Swendeman, Ingram, & Rotheram-Borus, 2009) on their own. This expectation is based on the assumption that if the medical aspects of HIV are addressed, PHAs can engage with life in a manner similar to the general population. Yet in this study, it was apparent that their social needs compounded their ability to manage their illness unaided. This research therefore made visible the invisible social aspects of HIV and its impact on PHAs' ability to fully incorporate theirHIV identity into their lives. These invisible needs became explicit to me by close association with participants, attending to their experiences, and visiting with them in social places. Without attending to life in the manner I did, and knowing PHAs in a personal way, it might be impossible for a health care provider to authoritatively know and plan for clients' needs.

Another issue that arose in the research related to how the participants related with Utumishi. Utumishi was integral to the stories participants lived and told, because it had single-handedly saved their lives through the provision of free antiretroviral medications. Since their enrollment in Utumishi services, the ASO had been a place where PHAs could receive free services and have their lives *fixed*. Because everything was done for them, some PHAs did not feel ownership in the programs. As such, they saw themselves as passive recipients of care and services. In this regard, John noted that:

> *Most of the patients still feel that they are coming to a program that is run by others and they are coming to get a service. If they could know that they are involved at some level in the decision making, then they would feel they own the program*

The fact that PHAs were not involved in the decision making of the ASO did not affect the commitment of the agency to provide high quality HIV care. However, the omission of PHAs in decision making, in contrast with GIPA principles, raised fundamental questions about the place of PHAs in the organizational hierarchy. Did PHAs associated with Utumishi lack the knowledge to contribute at higher levels? What were the social, academic, and economic standings of PHAs that were associated with the ASO? PHAs' lack of representation at the level of decision making meant that their voices and inputs were not factored in. This also created a possibility for communication breakdown in articulating policy and program changes. Hence, PHAs often found themselves unable to plan for and anticipate any changes within the ASO; occasionally feeling disenfranchised about their place in the ASO.

According to John, a lack of representation of PHAs at the senior levels of the ASO not only impinged on the principles of GIPA, but was also an indictment of the value PHAs held in the ASO and largely in the Kenyan society. John noted that a lack of a visible professional or a senior government official living publicly with HIV on the Utumishi board called into question the commitment to the GIPA principles. This absence may perhaps explain why the commitment to GIPA principles in Kenya is not as intense compared to the USA when the “nothing without us” movement began (Lune, 2007). Therefore, PHAs with less influence in society and who struggled with personal and socioeconomic issues such as Luanda, Nelly, Atoti, and Estero did, are left to shoulder the burden of promoting GIPA on their own.

Although participants were enthusiastic about their work as HIV lay workers, it was evident from their stories that financial considerations and limited options in gainful employment played a significant role in their decisions to take up these jobs. As lay workers, they were often confronted with HIV stigma, disclosure, and public scrutiny of their HIV identity. Knowing that Utumishi was perhaps the only employer that would unconditionally hire them knowing their HIV status, and without formal academic credentials, made them feel privileged. Undoubtedly, they had expressed dire financial need before they were hired at Utumishi. I wonder if they felt meaningfully involved as HIV lay workers given the circumstances that led them to seek these positions. Would they willfully work as HIV lay workers if they had viable alternative options outside of the ASO? Did they feel included in the ASO in a way that corresponds to GIPA's mantra "nothing for us without us" (Jürgen, 2008)? I also wondered about the moral-ethical imperatives that were at play in being paid as HIV lay workers to share personal HIV experiences.

Implications for Nursing Education

Relf and colleagues (2011) acknowledge that with about 33 million people living with HIV, a highly qualified nursing workforce is critical to addressing the health care needs of this population. In many parts of the world where HIV is pandemic, nurses play a critical role in HIV care, treatment, and prevention (Relf et al, 2011). Involvement of nurses in advanced HIV care which includes antiretroviral medication administration and monitoring has been caused by a shortage of physicians and a need to rapidly scale up HIV care programs (McCarthy, et al., 2013).

While the need for expanding and enhancing the role of nurses in HIV care is not in doubt, it is evident that nurses often do not receive sufficient HIV training (Knebel, Puttkammer, Demes, Devirois, & Prismy, 2008; Mill, et al., 2014). Furthermore, nurses have been reported to exhibit stigma and discriminative practices towards PHAs in care such as inappropriate application of universal precautions such as double gloving and wearing masks when caring for PHAs (Pickles, King, & Belan, 2009; Surlis, & Hyde, 2001; Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Others engage in unethical practices such as coercing clients to test for HIV, testing clients without consent or adequate counseling, and disclosing their HIV status to unauthorized people (Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010).

Although there was no evidence in this research that nurses engaged in unethical behaviors, there was a sense that the need for complex care for PHAs was often not well understood by nurses. Nurses can potentially engage in ethically responsive and culturally safe care if they have a deeper understanding of who PHAs are by engaging alongside them in relational ways. This is instructive, given that in an era where HIV is seen as a chronic illness, PHAs are able to live "normal" lives. Yet, they contend with immense socioeconomic and psychological challenges that significantly affected how they make sense of their HIV identities. In so doing, nurses' understanding of the "uncertainties," such as long-term use of antiretroviral medications, aging, and chronicity that PHAs face, may be enhanced. A plausible way to respond to the changes in HIV paradigms is to ensure that HIV content in nursing education is abreast with these changes.

Another way to educate nurses on HIV contemporary issues is to mainstream PHAs as HIV experts in HIV education endeavors. Experiential knowledge, a key to narrative pedagogy, recognizes and celebrates the power of personal storied experiences to transform, teach, educate, and inform practice (Binder, 2011). In attending to clients' experiences, collaborative practice as a shared understanding between a care provider and care receiver is fostered. This allows the client and provider to mutually identify what is educative (Huber, Caine, Huber, & Steeves, 2013; Pope, 2008). By focusing on and incorporating the lived experiences of clinicians, students, and teachers' within nursing education (Diekelmann, 2001; Nehls, 1995), clients' experiences and lives are also honored. Narrative pedagogies therefore can complement conventional and competency-driven pedagogy by focusing on human experience as drivers of change in practice (Maina, Sutankayo, Chorney, & Caine, 2014; Walsh, 2011).

In this research, the persuasive power of experiential knowledge was evident. Yet, it was only by attending to the experiences that participants lived and told that their pain, hopes, and aspirations became apparent. I became convinced that the experience of PHAs, in addition to being HIV educators to fellow PHAs, could greatly benefit health care providers. How to forge an educative partnership between nurses and PHAs needs to be further explored.

Turning to New Research

Engaging people living with HIV in narrative inquiry opened possibilities for me to think about how attending to these experiences could inform HIV care, policy development, and practice. In this process, several issues arose that require further exploration. First, in contexts where PHAs still struggle with the social effects of HIV infection, it is important to understand how GIPA as a concept has been taken up, especially in donor-funded programs. In so doing, opportunities and barriers for PHAs' involvement in HIV work can be explored to support a contextualized understanding and uptake of GIPA principles. In addition, the extent to which experiential knowledge in HIV work is acknowledged as a legitimate form of knowing needs to be understood.

Secondly, research to make HIV visible in an ever-changing HIV landscape, and at a time when antiretroviral medications are making HIV invisible, is needed. Although PHAs can live longer with HIV infection, this research has shown that PHAs care needs go beyond physical and medical needs. The invisible psychosocial effects of HIV infection continue to affect PHAs' ability to live positively with their illness. An understanding of how to best support PHAs in embracing and incorporating HIV as a positive identity is needed. In addition, the understanding of psychological benefits and effects of sustained public disclosure of HIV experiences by HIV lay workers is critically needed.

Lastly, considering that about 1.6 million people (6.5% of the population) live with HIV in Kenya, there might be an expectation that PHAs are a visible and influential community. Yet, from this research, it was obvious that PHAs are an invisible, and often marginalized constituency in relation to HIV work. This raises a fundamental question of the role, place, and the future of HIV activism in Kenya and ultimately the role of GIPA principles in the future.

Final Words

My experience inquiring into the experiences of four participants living with HIV was a journey full of wonders and surprises that transformed my outlook on the power of experiences. In attending to Luanda's, Atoti's, Nelly's, and Estero's stories to live by, I was confronted with sacred moments of vulnerability, adversity, and triumphs as we shared our lives and stories. I turn once more to Sartre's words:

> *A man is always a teller of tales,*
> *He lives surrounded by his stories and the stories of others.*
> *He sees everything that happens to him through them;*
> *And he tries to live his own life as if he were telling a story.*
> *But you have to choose: live or tell.*
> *(Jean-Paul Sartre, 1964)*

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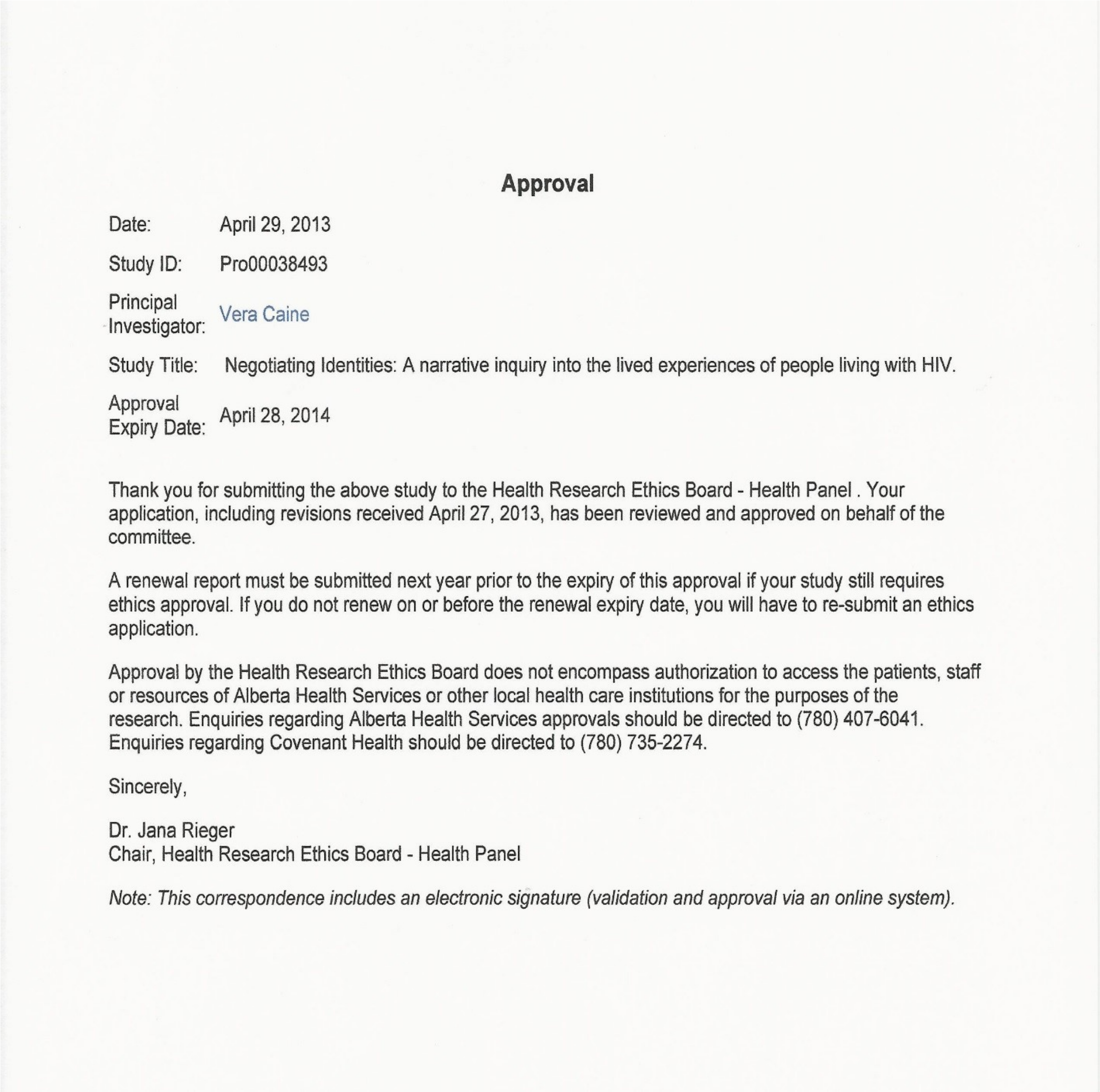
Appendix

Appendix 1: University of Alberta's Ethics approval



Approval

Date: April 29, 2013

Study ID: Pro00038493

Principal Investigator: Vera Caine

Study Title: Negotiating Identities: A narrative inquiry into the lived experiences of people living with HIV.

Approval Expiry Date: April 28, 2014

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, including revisions received April 27, 2013, has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

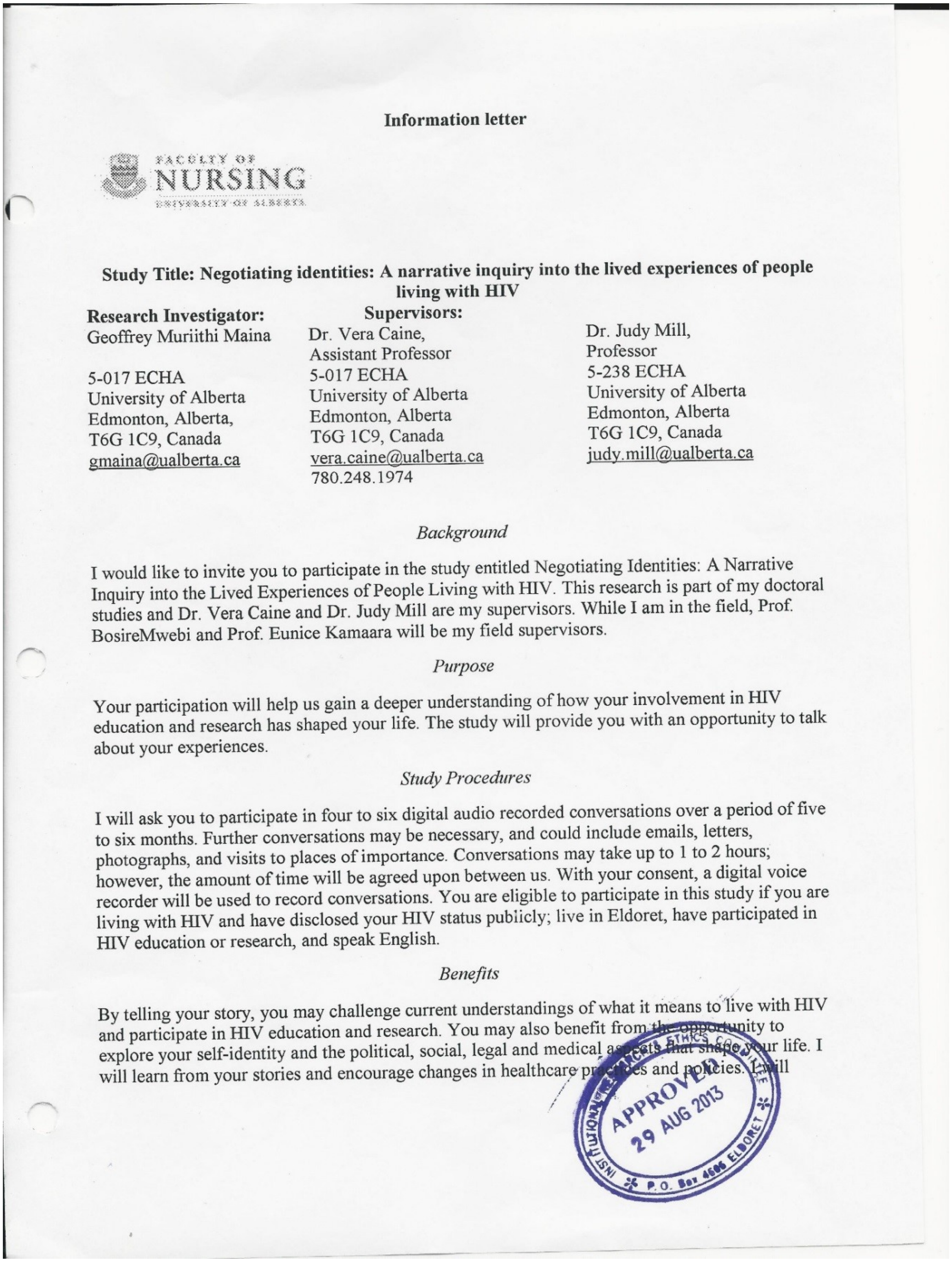
Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health should be directed to (780) 735-2274.

Sincerely,

Dr. Jana Rieger
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix 2: Information Letter



Information letter

FACULTY OF NURSING
UNIVERSITY OF ALBERTA

Study Title: Negotiating identities: A narrative inquiry into the lived experiences of people living with HIV

Research Investigator:
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Dr. Vera Caine,
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Dr. Judy Mill,
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T6G 1C9, Canada
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Background

I would like to invite you to participate in the study entitled Negotiating Identities: A Narrative Inquiry into the Lived Experiences of People Living with HIV. This research is part of my doctoral studies and Dr. Vera Caine and Dr. Judy Mill are my supervisors. While I am in the field, Prof. BosireMwebi and Prof. Eunice Kamaara will be my field supervisors.

Purpose

Your participation will help us gain a deeper understanding of how your involvement in HIV education and research has shaped your life. The study will provide you with an opportunity to talk about your experiences.

Study Procedures

I will ask you to participate in four to six digital audio recorded conversations over a period of five to six months. Further conversations may be necessary, and could include emails, letters, photographs, and visits to places of importance. Conversations may take up to 1 to 2 hours; however, the amount of time will be agreed upon between us. With your consent, a digital voice recorder will be used to record conversations. You are eligible to participate in this study if you are living with HIV and have disclosed your HIV status publicly; live in Eldoret, have participated in HIV education or research, and speak English.

Benefits

By telling your story, you may challenge current understandings of what it means to live with HIV and participate in HIV education and research. You may also benefit from the opportunity to explore your self-identity and the political, social, legal and medical aspects that shape your life. I will learn from your stories and encourage changes in healthcare practices and policies. I will

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reimburse costs incurred due to your participation in this study. Each time we have a digitally recorded conversation, I will provide you with **Kshs 400** for your expenses.

Risks

As you and I engage in talking about your experience, old and new emotions may surface. These stories may evoke feelings, which may swing between feelings of immense joy and happiness to a degree of sadness and loss. If any of these feelings do occur and you need support, the support services at HIV Edmonton will be available to you.

Voluntary Participation

You are under no obligation to participate in this study. Your participation is completely voluntary. Even if you agree to be in the study you can change your mind and withdraw at any time. The last possible circumstance for withdrawal of data from the study is following your reading of the final research text for publication. You can also request that a digital audio recorder may be shut off at any time.

Confidentiality

The research will be part of my dissertation for my doctoral studies. I will also publish research articles and presentations. I cannot guarantee your anonymity throughout the study; and changes made to names and places will be at your discretion. During our conversations, I will remind you to respect the identities of others disclosed in your stories and together, we would negotiate their representation in the final publication of the research text. However, pseudonyms will be used in the final publications where your name is referred to. Your stories and shared personal items will be kept confidential and will be handled by me, Dr. Vera Caine, Dr. Judy Mill and a transcriptionist.

The data for all uses will be handled in compliance with the University of Alberta Standards. I will keep all the data from this study in a locked cabinet, in my secure office for a minimum of 5 years following completion of the research project prior to any destruction. Feel free to let me know if you would like a copy of any forthcoming publications from this research.

Further Information

Should you need further questions regarding this study, please do not hesitate to contact myself at gmaina@ualberta.ca Dr. Vera Caine at 780.248.1974 or Dr. Judy Mill at 780. 492.7556.

If you have concerns about this study, you may contact the Research Ethics Office, at 780.492.2615. The Research Ethics office has no direct involvement with this project.

I am looking forward to work alongside you.

With kind regards, Geoffrey.

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